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The oral care experiences of palliative care patients, their relatives and healthcare professionals.

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**UNIVERSITY OF
PLYMOUTH**

**THE ORAL CARE EXPERIENCES OF PALLIATIVE
CARE PATIENTS, THEIR RELATIVES AND
HEALTHCARE PROFESSIONALS**

by

MARIA DO CARMO BERNARDES DELGADO

A thesis submitted to the University of Plymouth in partial
fulfilment for the degree of

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AUTHOR'S DECLARATION

At no time during the registration for the Research Masters has the author been registered for any other University award, without prior agreement of the Doctoral College Quality Sub-Committee.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

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Oral Care of Palliative Care Patients – Carers’ and Relatives’ Experiences.

ABSTRACT

The oral care experiences of palliative care patients, their relatives and healthcare professionals.

Maria do Carmo Bernardes Delgado

Background

Oral symptoms in a growing number of people receiving palliative care are often neglected. Dental professionals are not always involved in palliative care and research on oral care of palliative care patients is scarce. Oral care is often inadequately delivered to palliative care patients while oral health problems can affect quality of life.

Aims

To explore the experiences of palliative care patients, their relatives/carers and frontline healthcare professionals regarding the oral care received or provided.

Methods

Blogs and discussion forums were used as the data source. Data were analysed using thematic analysis. Subsequently a qualitative systematic review was conducted. Studies exploring the oral care experiences of adult patients, their relatives/carers or healthcare professionals were included. Finally, a qualitative study was performed in a hospice and four palliative care patients, four relatives and four healthcare professionals were interviewed. Transcripts were analysed using thematic analysis.

Findings

The study of blogs and discussion forums identified three themes: ‘symptoms’, ‘procedures’ and ‘emotions’. Oral care was provided as a reaction to oral symptoms, rather than pro-actively, to improve quality of life.

The qualitative systematic review identified that comfort seemed to be the goal of providing oral care. Patients, relatives and healthcare professionals reported different challenges in oral care. The psychological implications of patients were not able to speak, taste and swallow. The impact of oral symptoms and poor oral health did not seem to be acknowledged by relatives and healthcare professionals.

The qualitative interview study revealed three themes: ‘performing oral care’, ‘effects on oral health’ and ‘enablers and barriers to oral care’. Interpretation of these themes contributed to the understanding of the essence of the phenomenon being studied: the participants’ experiences of oral care. Relatives and healthcare professionals shared the view that oral care was important to deliver holistic person-centred care. They relied on past experiences of caring, but both groups perceived that education and training were lacking. Patients reported poor access to dental care. Barriers to self-care or other oral care was patients’ fatigue as experienced by all study participants.

Conclusions

The data from the three studies highlighted what the oral care experiences of palliative care patients, their relatives and healthcare professionals are, within a context. Despite some commonalities, the oral care experiences tended to be different between the three groups. Oral care was considered an important part of delivering holistic care. Good oral care practices were identified that might be transferable to other settings where palliative care patients are cared for.

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CHAPTER 1: Introduction

1.1 Introduction to the thesis

The World Health Organisation states that palliative care provides relief from pain and other symptoms, enhances quality of life for patients and can influence positively the course of the illness (WHO, 2004a). Palliative care integrates multiple aspects of patient care such as psychological and spiritual aspects and offers a support system for both patients and family. As argued by Dame Cicely Saunders, palliative care helps patients to live until they die and what is important is quality of life, rather than quantity (Randall & Downie, 2006).

Despite the known benefits of palliative care, access is still inadequate even in high-income countries (Etkind *et al.*, 2017). People in European and other developed countries are living longer and those living beyond 65 years of age are increasing proportionally (WHO, 2004a). It is expected that by 2030, 22% of the population in England and Wales will be aged 65 years or older and this is similar to other nations (Gomes & Higginson, 2008). Alongside these demographic changes, pattern of diseases is also changing such as an increase, worldwide, in long-term conditions and multi-morbidity (Etkind *et al.*, 2017; WHO, 2004a). Furthermore, incidence, prevalence and mortality of chronic illnesses is rising globally and it is predicted that the need for palliative care will continue to grow (Etkind *et al.*, 2017; WHO, 2004a).

Etkind *et al.* (2017) projected that by 2040, in England and Wales, between 25% and 47% more individuals are likely to need palliative care. According to the most conservative projection, which assumes that age and sex-specific proportions of deaths

requiring palliative care will remain the same as in 2014, the number of people requiring palliative care will grow from 375,398 individuals in 2014 to 469,305 individuals by 2040. This equates to a 25% increase. The increase in need for palliative care is due to an overall increase in population numbers, projected rise in death from chronic illnesses and more deaths occurring at older ages. Moreover, the main conditions accounting for this projected growth in demand are dementia and cancer. Despite this rise in demand, access to palliative care is inconsistent and only a minority of those who need it will receive palliative care. It is suggested that only 14% of people who need palliative care globally receive it (Etkind *et al.*, 2017).

The evidence on the need for palliative care is generally of poor quality and can provide conflicting results (Franks *et al.*, 2000). The different methods used to assess need present several limitations such as the great variation of prevalence of symptoms amongst patient groups with similar disease profiles and the failure to identify type of care required when the evidence is based only on prevalence of symptoms.

Nevertheless, it seems unquestionable that there will be a growth in demand for palliative care services worldwide and also in the UK. In addition, the WHO (2004a) states that palliative care should be initiated from the time of diagnosis onwards and not only during the last few weeks of life. Palliative care services should be available based on need in terms of symptoms and problems and not only at an easily definable period before death.

Palliative care has been defined as a “*patient-centred approach to care in advanced disease, focusing on quality of life and relief of symptoms*” (Etkind *et al.*, 2017, p.1).

However, it seems that some of the most common symptoms palliative care patients experience are not being addressed appropriately (Kvalheim *et al.*, 2016; NHS Scotland, 2014). It is known that oral symptoms are amongst the most common problems

palliative care patients face (Kinley & Brennan, 2004; Kvalheim *et al.*, 2016; Milligan *et al.*, 2001; NICE, 2018; Wiseman, 2000). Nonetheless, these symptoms are often overlooked (Saini *et al.*, 2009). The oral care delivered to palliative care patients is frequently inadequate (Kvalheim *et al.*, 2016) and it is also often neglected (NHS Scotland, 2014) despite the known consequences of oral health problems for quality of life (Lee *et al.*, 2001; Wiseman, 2000). The consequences of poor oral health are not limited to the oral cavity and can lead to life-threatening conditions such as endocarditis (Lockhart *et al.*, 2009; Pallasch & Slots, 2000), bacteraemia (Gonzalez Navarro *et al.*, 2017) and aspiration pneumonia (Langmore *et al.*, 2002). Indeed, the mortality rate of aspiration pneumonia is reported to be between 20% and 50% (Langmore *et al.*, 1998). Given the impact of poor oral health on individuals' quality of life, particularly those that are medically-compromised, such as palliative care patients, it is pertinent to understand the current situation regarding the oral care of palliative care patients. A research project to investigate this problem was developed and is described in this thesis. This introductory chapter provides the historical context of palliative care, the definition of different concepts such as palliative care and end-of-life care. This chapter also presents what is known regarding the oral care of palliative care patients and defines the initial research problem.

1.2 Historical context for palliative care

Modern palliative care started with the hospice movement in the twentieth century (Abu-Saad, 2001). However, palliative care can trace its origins to the ancient hospices that arose in the fourth century or indeed to the Asklepian School in ancient Greece (Randall & Downie, 2006). Asklepius, similarly to Hippocrates, developed an ancient

Greek medical school (Randall & Downie, 2006). While the Hippocratic medical tradition was concerned with the scientific basis of medicine, the Asklepiian medical tradition focused on relief from suffering and the acceptance of one's mortality (Randall & Downie, 2006).

In 335 AD, Constantine, the first Christian Roman emperor, decreed the founding of infirmaries, known as *nosocomeia*, throughout the empire (Abu-Saad, 2001). These were centuries later called *hospicia* and could be found in the Mediterranean area. Some religious orders, such as the Benedictines in the sixth century, were known for their hospices. Monks cared for pilgrims and gradually hospices also became places of refuge for the sick and terminally-ill. The practice of medicine was elementary, therefore the sick, when cure was not possible, were cared for with food, kindness, shelter, and religious services.

During the Reformation the support of monasteries faded and secular physician groups took over some of the services provided by hospices (Abu-Saad, 2001). Hospitals developed in later centuries and with growing medical technology, holistic care did not receive much attention. The emphasis was on cure (Abu-Saad, 2001) and death was seen as a failure by clinicians (Lawton, 2000). Nevertheless, during the 1960s the philosophy of holistic care and a patient-centred approach emerges once again with Dame Cicely Saunders in the UK (Randall & Downie, 2006). At the time, patients dying from cancer for whom all curative measures had been exhausted, were being overlooked or abandoned by healthcare professionals (Clark, 2007). Individuals dying were rarely informed of their prognosis and healthcare professionals (HCPs) often avoided contact with them altogether (Lawton, 2000). Dame Cicely Saunders focused on these patients and was instrumental in the development of new knowledge on how to care for them (Clark, 2007). She also promoted the relief of *total pain*, which could only

be achieved with an interdisciplinary team approach (Loscalzo, 2008; Randall & Downie, 2006). The whole person and family are at the centre of hospice medicine, not the diseased organ (Overy & Tansey, 2013).

The opening of St Christopher's Hospice in London in 1967, by Dame Cicely Saunders, led to the first steps being taken towards the modern hospice movement in the UK, its development in the USA and later, in more than 50 countries around the world (Abu-Saad, 2001). In 1987 palliative medicine became a formal medical speciality in the UK.

Palliative care is often delivered by non-specialists (Etkind *et al.*, 2017) and individual patient needs will usually dictate the way in which the care is provided. It can be delivered for example in a primary care setting as advance care planning or in secondary care for symptom management. Those individuals with more complex needs are looked after by specialist multidisciplinary palliative care teams in a variety of settings such as hospitals, hospices and in the community.

1.3 Palliative care

The historical context of palliative care has been briefly presented. The following section presents the definitions of some of the concepts used throughout this thesis and the context in which they are used.

The term palliative has its origins in the Latin word *pallium*, which means cover or cloak (Abu-Saad, 2001). It was first used in medicine, in the 16th century, to describe mitigation of suffering and this is how the term is still used today.

The early modern hospices provided palliative care for individuals, usually adults, with a cancer diagnosis (Baldwin & Woodhouse, 2011). Nowadays palliative care is not

limited to oncological patients (Loscalzo, 2008). In fact, the WHO (2004a) argues that given the effectiveness of palliative care, it should be offered to all of those living with serious chronic conditions. However, there is not yet a consensus regarding the definition of palliative care, when it should be applied, to whom and by whom (IAHPC, 2018). This makes its implementation challenging.

The International Association for Hospice and Palliative Care (IAHPC) presented a new global consensus definition of palliative care in 2018:

‘Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

Palliative care:

- *Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.*
- *Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.*
- *Is applicable throughout the course of an illness, according to the patient’s needs.*
- *Is provided in conjunction with disease modifying therapies whenever needed.*
- *May positively influence the course of illness.*
- *Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.*
- *Provides support to the family and the caregivers during the patient’s illness, and in their own bereavement.*
- *Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.*
- *Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).*
- *Can be provided by professionals with basic palliative care training.*

Requires specialist palliative care with a multi-professional team for referral of complex cases. ' (IAHPC, 2018)

Nonetheless, this definition is not without criticism, namely from the European Association of Palliative Care, which states that the definition does not reflect the complexity of palliative care (EAPC, 2019).

Table1 includes further definitions of palliative care and other associated concepts. It highlights the number of existing definitions, how some concepts are used differently in different countries and ultimately, the challenges in defining some concepts, given the existing confusion in the literature.

Table 1 – Palliative care and associated concepts: further definitions

Concepts	Definitions
Palliative care	<p>‘...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’ (WHO, 2004a, p.14)</p> <p>‘End of life care includes palliative care. If you have an illness that can't be cured, palliative care makes you as comfortable as possible, by managing your pain and other distressing symptoms. It also involves psychological, social and spiritual support for you and your family or carers. This is called a holistic approach, because it deals with you as a "whole" person, not just your illness or symptoms. Palliative care isn't just for the end of life – you may receive palliative care earlier in your illness, while you are still receiving other therapies to treat your condition.’ (NHS, 2018)</p> <p>‘Palliative care is treatment, care and support for people with a life-limiting illness, and their family and friends. It’s sometimes called ‘supportive care’. The aim of palliative care is to help you to have a good quality of life – this includes being as well and active as possible in the time you have left. It can involve: managing physical symptoms such as pain; emotional, spiritual and psychological support; social care, including help with things like washing, dressing or eating; support for your family and friends. A life-limiting illness is an illness that can’t be cured and that you’re likely to die from. You might hear this type of illness called ‘life-threatening’ or ‘terminal’. People might also use the terms ‘progressive’ (gets worse over time) or ‘advanced’ (is at a serious stage) to describe these illnesses. Examples of life-limiting illnesses include advanced cancer, motor neuron disease (MND) and dementia. You can receive palliative care at any stage in your illness. Having palliative care doesn’t necessarily mean that you’re likely to die soon – some people receive palliative care for years. You can also have palliative care alongside treatments, therapies and medicines aimed at controlling your illness, such as chemotherapy or radiotherapy. However, palliative care does include caring for people who are nearing the end of life – this is sometimes called end of life care.’ (Marie Curie, 2016)</p>

Hospice care	‘Hospice in the USA became a concept of care rather than a place of care...The term palliative care was gradually brought into the lexicon as a synonym of hospice care.’ (Abu-Saad, 2001, p.43)
End-of-life care	<p>‘People are approaching the end of life when they are likely to die within 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:</p> <ul style="list-style-type: none"> • Advanced, progressive, incurable conditions. • General frailty and co-existing conditions that mean they are expected to die within 12 months. • Existing conditions if they are at risk of dying from sudden acute crisis in their condition. • Life threatening acute conditions caused by sudden catastrophic events.’ (GSF, 2016) <p>‘End of life care involves treatment, care and support for people who are nearing the end of their life. It’s an important part of palliative care. It’s for people who are thought to be in the last year of life, but this timeframe can be difficult to predict. Some people might only receive end of life care in their last weeks or days. End of life care aims to help you to live as comfortably as possible in the time you have left. It involves managing physical symptoms and getting emotional support for you and your family and friends. You might need more of this type of care towards the end of your life. End of life care also involves talking to you and your family and friends about what to expect towards the end of your life. The people looking after you will talk to you about your needs and wishes, and make sure they consider what you want in the care they provide. It can also involve support with practical things like making a Will or getting financial support.’ (Marie Curie, 2016)</p>
Terminal-illness	‘A terminal illness is a disease or condition which can’t be cured and is likely to lead to someone’s death. It’s sometimes called a life-limiting illness.’ (Marie Curie, 2019)
Palliative oral care or palliative care dentistry	‘the management of patients with far advanced disease where the oral cavity has been compromised, either directly by the disease or indirectly as a consequence of its treatment’ (Kvalheim <i>et al.</i> , 2016, p.522)

In this thesis the population of interest are palliative care patients as opposed to end-of-life patients. Palliative care is a broader concept than end-of-life care. This in itself can create some challenges in understanding who qualifies as a ‘palliative care patient’.

However, end-of-life care was considered an even more challenging concept.

End-of-life care is a crucial part of palliative care for people who are nearing the end of their life. As per the definitions presented above, it is understood that end-of-life care is for those individuals who have less than 12 months to live. This timeframe is difficult to predict. In addition, this concept is open to various interpretations. End-of-life care can often be associated exclusively to those whose death is imminent. Furthermore, there are experts who argue that palliative care should be decoupled from end-of-life (Meier, 2013). Professor Meier, for instance, argues about a fundamental shift in message, from improving care of the dying to improving quality of life for those living with serious illness. It is often the case that people will not accept the end-of-life label (Meier, 2013).

Palliative care patients were chosen as the population of interest instead of terminally-ill patients. This resulted from feedback received from healthcare professionals and the users’ group during a Patient and Public Involvement (PPI) consultation at a hospice in the South-West of England. The advice given was not to use the term ‘terminally-ill patients’. It was deemed that it could have all sorts of interpretations and was also outdated. Crucially this term could be upsetting for patients and ‘palliative care patients’ is a more sensitive approach to both patients and their families.

Despite the challenges in defining ‘palliative care patients’ this is the term that will be used throughout this thesis and as stated above this is the population of interest for the research presented in this thesis.

1.4 Dental care of palliative care patients

The oral health of an individual is a reflection of their general health (NICE, 2018).

Therefore, the deterioration of an individual's oral health becomes increasingly more prevalent with advancing illnesses (NICE, 2018). Oral health conditions range from active dental caries in 20% to 33% of palliative care patients (Saini *et al.*, 2009) to candidiasis and xerostomia or dry mouth (NICE, 2018). It is argued that the quality of life of palliative care patients is greatly affected by oral health problems and these can precipitate further complications such as anorexia, malnutrition, cachexia and even aspiration pneumonia (Lee *et al.*, 2001; Wiseman, 2000). These are potentially life-threatening conditions, particularly to already medically-compromised patients. An impaired host response, compromised lung function and needing help eating are all risk factors to developing aspiration pneumonia (Terpenning *et al.*, 2001). In addition, dental decay, cariogenic and periodontal pathogens are also important risk factors for aspiration pneumonia, which presents a very high mortality rate (Langmore *et al.*, 1998; Terpenning *et al.*, 2001). Furthermore, poor oral health can have an impact on self-esteem, social interaction and depression, which affect wellbeing and general health (Hakeem, Bernabe & Sabbah, 2019). Poor oral health is also one of the indicators of frailty (Hakeem, Bernabe & Sabbah, 2019). Frailty is characterised by reduced physiological reserve and leads to adverse health outcomes such as dependency, cognitive decline, functional impairment and ultimately death (Hakeem, Bernabe & Sabbah, 2019).

Despite the enormous implications of poor oral health, particularly to frail and medically-compromised individuals, the oral care provided to palliative care patients is not always a priority (Kvalheim *et al.*, 2016) and it is often a forgotten aspect of these patients' care (NHS Scotland, 2014). Some argue this is due to lack of resources, time

pressures and inadequately trained staff (Kvalheim *et al.*, 2016). In addition, the guidance available is scarce and frequently not based on evidence but on expert opinion. The WHO (2004b) issued guidelines in order to assist health workers, community care providers and family members to provide home-based palliative care. This includes preventative oral care such as tooth brushing and management of key symptoms such as painful mouth ulcers, pain on swallowing and dry-mouth. Still, the advice given is limited and it is not clear whether it is evidence-based. Similarly the National Institute for Health and Care Excellence (NICE, 2018) provides guidance regarding palliative oral care. Nonetheless, several sections of this guidance document, such as self-care, dry-mouth management and oral pain, are pragmatic recommendations and based on expert opinion.

A review of the literature demonstrated similar findings and most articles were not empirical studies. Instead they were mainly narrative reviews and audits. Most articles published on the oral care of palliative care patients focused on the management of commonly occurring oral problems, such as xerostomia, mucositis and candidiasis (Quinn, 2013; Rohr, Adams & Young, 2010; Sargeant & Chamley, 2013; Wiseman, 2000; Wiseman, 2006). There were also papers on audits to current practices and local guidelines implemented in both hospice and hospital settings (Kinley & Brennan, 2004; Lee *et al.*, 2001; Milligan *et al.*, 2001). In addition some researchers sought to explore the knowledge, perceptions and practices of nursing staff (Couch, Mead & Walsh, 2013; Croyere *et al.*, 2012; Kvalheim *et al.*, 2016). Palliative care patients' point of view and experiences regarding their oral care was only explored in one paper found during the literature review (Rohr, Adams & Young, 2010).

Despite the heterogeneity of the articles identified in the literature search, most authors had similar conclusions. In palliative care patients the oral cavity, is commonly the first

site of discomfort and loss of function (Chen *et al.*, 2013a; Couch, Mead & Walsh, 2013; Croyere *et al.*, 2012; Kinley & Brennan, 2004; Kvalheim *et al.*, 2016; Lee *et al.*, 2001; Milligan *et al.*, 2001; Rohr, Adams & Young, 2010; Saini *et al.*, 2009; Wiseman, 2000; Wiseman, 2006). Additionally, it was argued that dental professionals should be playing a more active role in providing care for these individuals (Chen *et al.*, 2013a; Quinn, 2013; Saini *et al.*, 2009; Wiseman, 2006). Moreover, some authors agreed palliative oral care must be improved and standardised (Couch, Mead & Walsh, 2013; Kinley & Brennan, 2004; Rohr, Adams & Young, 2010). Lastly, Kvalheim *et al.* (2016) stated that there is a certain degree of confusion surrounding palliative oral care. This may be due to the lack of evidence on which to base oral care procedures for palliative care patients.

1.5 Rationale for research

The evidence reported to date demonstrates that there is an increasing number of individuals requiring and likely to benefit from palliative care, yet some of the most common symptoms these individuals experience, i.e. oral problems, are often being neglected. Moreover, dental professionals are not always involved in the care of these patients (Saini *et al.*, 2009; Wiseman, 2006) and research on the oral care of palliative care patients is scarce and frequently not evidence-based (Kvalheim *et al.*, 2016). Furthermore, the experiences of the individuals receiving palliative oral care, their relatives, carers and HCPs has rarely been sought. It is also acknowledged that the difference between dental professionals' research priorities and what patients and those providing oral care value is often not taken into consideration (NICE, 2016). Thus, it appears that there is little evidence available either on the type of oral care provided to

palliative care patients or whether the oral care provided is considered adequate and crucially what the experiences of patients, carers, families and HCPs are.

Consequently, in order to address this lack in knowledge, the present research project aims to explore the experiences of palliative care patients, their relatives, carers and HCPs regarding the oral care received or provided.

1.6 Research questions, aims and objectives

This research project aimed to answer the following questions:

- What are the oral care experiences of patients during palliative care?
- What are the experiences of those who provide oral care or support palliative care patients in their oral care, such as relatives, carers and HCPs?

The aims were:

- To explore and better understand the oral care experiences of palliative care patients;
- To explore the oral care experiences of relatives/carers of palliative care patients and of HCPs.

In order to achieve the aims, set above, the researcher conducted a study of blogs and discussion forums, a qualitative systematic review and an interview study. These will be described, and their findings presented in chapters two, three and four respectively.

1.7 Summary

In this chapter the historical context of palliative care, the definition of different concepts and how they are going to be used in this thesis have been described. The growth in demand for palliative care services worldwide and in the UK has also been highlighted. The rationale for the study and the limited research exploring oral care experiences of palliative care patients have been addressed.

Chapter2 describes and presents the results of a qualitative study of blogs and discussion forums that explored the oral care experiences of palliative care patients. This was an exploratory study in order to understand what was being said regarding the oral care of palliative care patients. The topic was explored from the perspective of relatives and carers of palliative care patients as it was concluded that palliative care patients would be less likely to keep a blog throughout the entire course of their illness. At this stage of the research project it was important to understand both the language individuals were using and the topics they were focusing on.

The study was published in the British Dental Journal and informed the qualitative systematic review conducted subsequently, namely with the identification of search terms.

Chapter3 describes and presents the findings of a qualitative systematic review on the oral care experiences of palliative care patients, their carers/relatives and HCPs. This review explored the oral care experiences from the perspective of palliative care patients, relatives and HCPs. The qualitative systematic review identified that HCPs and relatives failed to perceive the wider impact of oral problems on the quality of life of patients. In addition, palliative care patients, relatives and HCPs seemed to experience different challenges in relation to oral care.

Chapter 4 presents a qualitative study conducted in a hospice in the South-West of England, where patients, relatives and HCPs were interviewed regarding their oral care experiences or the oral care experiences of their clients and relatives. The analysis and interpretation of the data contributed to the understanding of the essence of the phenomenon of interest: the participants' experiences of oral care. One of the biggest barriers to self-care or other oral care was patient fatigue. This was a barrier that relatives and HCPs found extremely hard to overcome.

Chapters 3 and 4 are presented as nearly ready to submit manuscripts. It was considered important, for the purposes of this thesis, to thread the chapters together rather than presenting them as separate pieces of research and completely separate articles.

Finally, the last chapter presents a summary of the findings of the three studies, their implications to patient care and recommendations for dental practice, education and research.

CHAPTER 2: Oral care of palliative care patients – carers’ and relatives’ experiences. A qualitative study.

This chapter describes a qualitative study of blogs and discussions forums on the oral care of palliative care patients. The patients mentioned in all the blogs and most of the discussion forums included were terminally-ill and receiving end-of-life care.

This chapter, presented as a paper, was accepted and published in the peer-reviewed journal the British Dental Journal:

Bernardes Delgado, M., Burns, L., Quinn, C., Moles, D. R. and Kay, E. J. (2018): Oral care of palliative care patients - carers' and relatives' experiences. A qualitative study.

British Dental Journal, 224 (11): 881-886.

doi: 10.1038/sj.bdj.2018.434

A description of the work and an estimated percentage of contribution of each author are as follows: Bernardes Delgado, M. (90%), Burns, L. (2.5%), Quinn, C. (2.5%), Moles, M. R. (2.5%), Kay, E. J. (2.5%). These percentages have been agreed amongst all authors. Letters from all authors confirming contribution to the publication are included as appendices (Appendix 1).

MBD generated the initial idea and research problem, screened the blogs and discussion forums for eligibility, analysed the data and drafted the first manuscript. LB helped MBD develop the search strategy and CQ acted as a second reviewer. All authors have contributed and agreed the final manuscript.

**Oral care of palliative care patients – carers’ and relatives’
experiences. A qualitative study.**

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2.1 Abstract

Introduction: The oral cavity, in palliative care patients, is commonly the first site of discomfort and loss of function. Oral care, however, is often overlooked for these patients. Palliative oral care is a poorly researched area and the experiences of patients, their carers and relatives are seldom explored.

Aims: To explore the oral care experiences of palliative care patients, from the perspective of their carers and/or relatives.

Methods: Blogs and discussion forums, on public internet sites, were used as the data source. Data were analysed using thematic analysis.

Results: Eight blogs and eight discussion forums fulfilled the inclusion criteria and were analysed. Three main themes were identified: symptoms, procedures and emotions. Authors described oral symptoms that they could observe themselves and perceived as being distressing. There was an association between oral care procedures and the oral symptoms observed. However routine oral care procedures were poorly described.

Conclusion: The data on oral care provided by the blogs and discussion forums included was scarce. It provided, however, preliminary insights into this poorly researched area. In this group, the importance of oral care for terminally-ill patients was frequently overlooked until the person's quality of life became compromised by their oral symptomatology.

Key points:

- Draws attention to the poorly researched area of palliative oral care;

- Identifies common themes, regarding oral care of palliative care patients, reported in blogs and discussion forums written by relatives;
- Provides insight into palliative oral care and how future research could be designed.

2.2 Introduction

Oral symptoms are amongst the most common problems palliative care patients face (Kinley & Brennan, 2004; Kvalheim *et al.*, 2016; Milligan *et al.*, 2001; NICE, 2018). Oral health complaints become increasingly prevalent with advancing illnesses (NICE, 2018). These range from active dental caries in 20% to 33% of palliative care individuals (Saini *et al.*, 2009) to candidiasis and dry-mouth (NICE, 2018). Lee *et al.* (2001) and Wiseman (2000) state that the quality-of-life of terminally-ill patients is greatly affected by oral health problems and that these can precipitate further complications. Consequently, it is argued that oral health needs, must be taken into account when planning for someone's end-of-life care (Chen *et al.*, 2013a; NHS Scotland, 2014).

The General Medical Council (GMC) in the UK provides a definition of end-of-life care: 'People are approaching end-of-life when they are likely to die within the next 12months. This includes people whose death is imminent (expected within a few hours or days) and those with advanced, progressive, incurable conditions; general frailty and co-existing conditions that mean they are expected to die within 12 months; existing conditions if they are at risk of dying from sudden acute crisis in their condition; life-threatening acute conditions caused by sudden catastrophic events.' (GSF, 2016)

Terminally-ill individuals are likely to be receiving palliative care to help managing and reducing their symptoms (Marie Curie, 2016). Palliative care is 'an approach that improves the quality-of-life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' (WHO, 2004a, p.14)

The WHO (WHO, 2004b) issued guidelines in order to assist health-workers, community care providers and family members to provide home-based palliative care. This includes preventative oral care such as tooth brushing and management of key symptoms such as painful mouth ulcers, pain on swallowing and dry-mouth. However, the advice given is limited and it is not clear whether it is evidence-based.

Similarly in England the National Institute for Health and Care Excellence (NICE, 2018) provides guidance regarding palliative oral care. Palliative oral care is ‘the management of patients with far-advanced disease where the oral cavity has been compromised, either directly by the disease or indirectly as a consequence of its treatment’ (Kvalheim *et al.*, 2016, p.522). Several sections of the document, such as self-care, dry-mouth management and oral pain, are pragmatic recommendations and based on expert opinion. The advice provided by NICE (2018) regarding oral care for terminally-ill patients is also based partly on expert opinion rather than evidence.

It is argued that the oral care delivered to palliative care patients is not always adequate (Kvalheim *et al.*, 2016). NHS Scotland (2014) have stated that oral care is often neglected for palliative care patients. Some argue this is due to inadequately trained staff, lack of resources and time pressure (Kvalheim *et al.*, 2016). Moreover, the guidance available is frequently not based on evidence but on expert advice.

A review of the available literature showed that articles published in the palliative oral care field focused on the management and report of commonly occurring oral problems (Quinn, 2013; Rohr, Adams & Young, 2010; Sargeant & Chamley, 2013; Wiseman, 2000; Wiseman, 2006). Most authors presented similar conclusions. The oral cavity, in palliative care patients, is commonly the first site of discomfort and loss of function (Chen *et al.*, 2013a; Couch, Mead & Walsh, 2013; Croyere *et al.*, 2012; Kinley & Brennan, 2004; Kvalheim *et al.*, 2016; Lee *et al.*, 2001; Milligan *et al.*, 2001; Quinn,

2013; Rohr, Adams & Young, 2010; Saini *et al.*, 2009; Wiseman, 2000). Additionally, it was argued that dental professionals should be playing a more active role in providing care for these individuals (Chen *et al.*, 2013a; Quinn, 2013; Saini *et al.*, 2009; Wiseman, 2006). Moreover, some authors have stated that palliative oral care must be improved and standardised (Couch, Mead & Walsh, 2013; Kinley & Brennan, 2004; Lee *et al.*, 2001; Milligan *et al.*, 2001; Rohr, Adams & Young, 2010). Lastly, Kvalheim *et al.* (2016) reported that there is a certain degree of confusion surrounding palliative oral care. This fact can be explained by the lack of evidence on which to base procedures (Kvalheim *et al.*, 2016).

NICE (2016) issued oral health guidelines for adults in care homes, where it recognised that research in oral health focuses primarily on clinical dental indices. The difference between dental professionals' research priorities and what the individuals receiving and providing oral care value is rarely taken into consideration (NICE, 2016) This suggests that the care provided may not be patient-centred.

Research on palliative oral care is scarce and the perspective of patients, relatives and carers has rarely been sought. Consequently, the aim of this study is to explore the oral care experiences of palliative care patients, from the perspective of their relatives and/or carers. Blogs and discussion forums, on public internet sites, were used to access data. This approach was chosen to avoid causing additional burden to this already compromised population. Terminally-ill patients, who require support or cannot perform basic oral care procedures, are unlikely to be able to keep a blog themselves. Hence this study examined the relatives and/or carers' reports.

2.3 Methods

Theoretical approach

The aim of this research is to explore the experiences of relatives and/or carers of terminally-ill patients regarding their oral care. The researcher adopted a contextualist epistemological position. The contextualist position, sits between essentialism and constructionism (Braun & Clarke, 2006). It asserts that there is not a single reality, but that people make meaning of their experience and that social context also influences those meanings, while simultaneously retaining focus on the reality (Braun & Clarke, 2006). A phenomenological approach was adopted to study the ‘lived’ subjective experiences of the carers and/or relatives. The textual data, found in blogs and discussion forums, provided useful sources in exploring the hermeneutics of these peoples’ experiences (Keim-Malpass, Steeves & Kennedy, 2014).

Ethical considerations

The internet is undoubtedly the most comprehensive source of written material and easily accessed data (Keim-Malpass, Steeves & Kennedy, 2014). Data can be generated without researchers interacting directly with participants, which bypasses some of the ethical concerns (Braun & Clarke, 2013). However, despite blogs and discussion forums being in the public domain, some authors argue that consent is still required (Braun & Clarke, 2013). Hence, for the purposes of this study, the researcher analysed data that was on public internet sites. All data collected and analysed were kept anonymous.

Data collection

The search strategy was developed with the help of an information specialist. An electronic search using ‘Google’ and known blog platforms such as ‘Tumblr’ and

‘Wordpress’ was conducted on January 25th, 2017. The search terms used, and search history can be found in Appendix2.

Blogs and discussion forums were selected using the following inclusion criteria:

- Blogs and discussion forums available on public internet sites;
- Authors are relatives and/or carers of palliative care patients, not HCPs;
- Authors are over 18 years old;
- Oral care must be mentioned, even if the author writes about other topics;
- Blogs and discussion forums are written in English.

The search strategy resulted in twenty blogs and discussion forums being retrieved.

After the removal of duplicates nineteen blogs and discussion forums were considered potentially eligible. Two blogs and one discussion forum were excluded after full-text analysis. One of the excluded blogs was written by a HCP and the other described the signs of imminent death: ‘...*his mouth open. Staring into space.*’

A discussion forum for carers which did not mention oral care was excluded from the study.

Eight blogs and eight discussion forums met the inclusion criteria and were analysed (Figure1). All authors were relatives of palliative care patients. Eleven authors were also carers, one author was not a carer and it was not clear in four discussion forums.

Seven of the eight blogs were written by females and seven were written in the USA.

All palliative care patients mentioned in the blogs were terminally-ill and the deaths of seven were recounted within the blogs. Six of the eight discussion forums were started by females and all were written in the UK.

Six of the eight palliative care patients mentioned were terminally-ill and the deaths of three were mentioned within the discussion forums. Demographic data are presented in Appendix3.

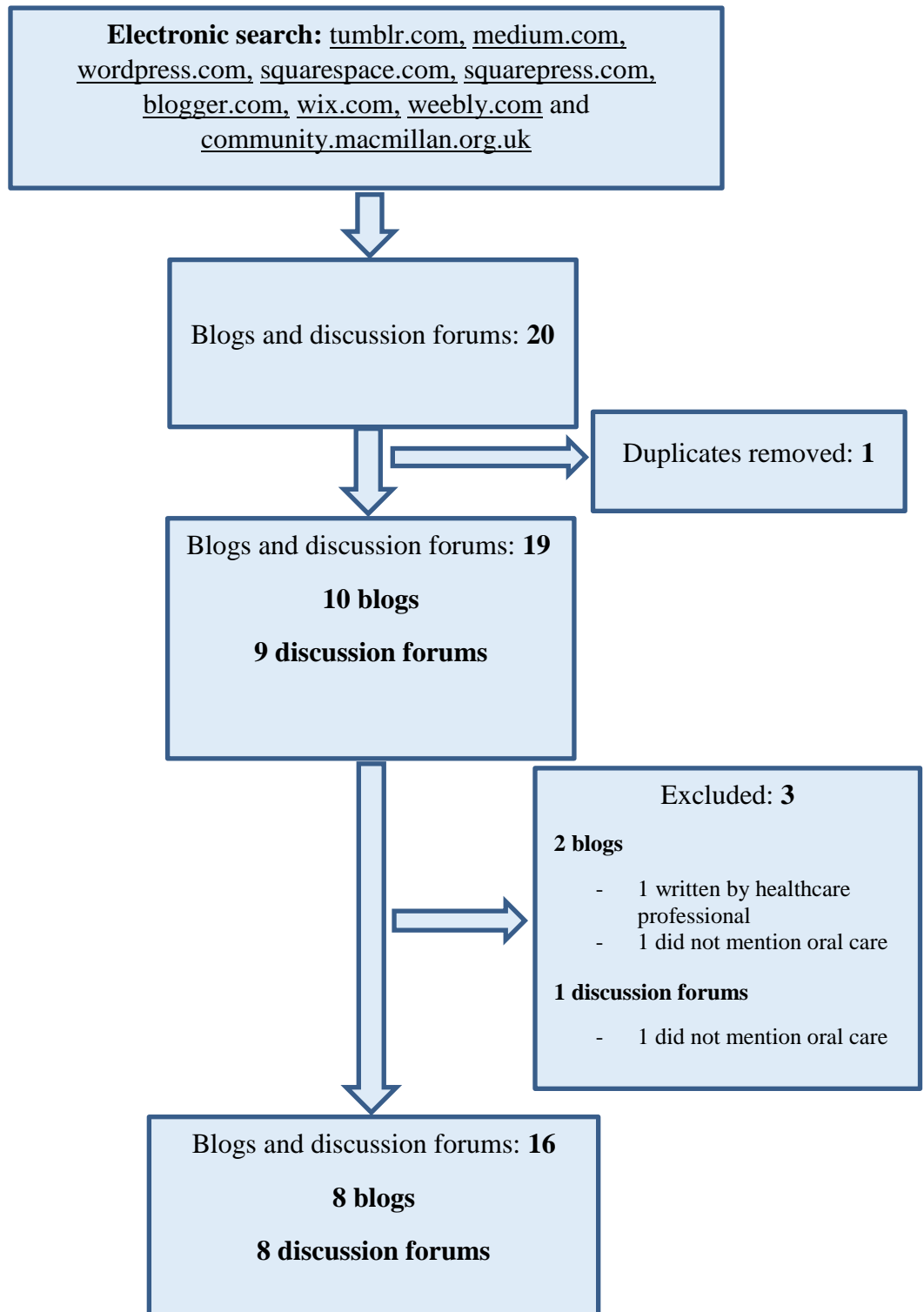


Figure 1: Selection process of blogs and discussion forums

Data analysis

The method chosen to analyse the data was thematic analysis. This method is not restricted to a single theoretical framework and can be used with a number of theoretical and epistemological positions, including a contextualist epistemological position and a phenomenological approach (Braun & Clarke, 2013). It is also described as being a flexible foundational data analysis method, accessible to new researchers (Braun & Clarke, 2013).

Nonetheless Braun and Clarke (2006) offer guidance and the researcher followed the six phases described by these authors. MBD undertook a process of data immersion by reading each of the texts, in their entirety, several times and then focusing on the sections referring specifically to oral care. These sections were then extracted, retaining sufficient surrounding text to ensure comprehensiveness of meaning and initial codes were produced. Subsequently, MBD sorted the different codes into potential themes. This resulted in candidate themes, multiple sub-themes and all the extracts of data that had been coded. The candidate themes were then refined. During this phase, MBD reviewed all the extracts of data for each candidate theme. In addition, MBD re-read the entire data set and a second reviewer (CQ), reviewed the themes, sub-themes and data extracts. This ensured rigour.

2.4 Findings

Oral care was not the main topic in any of the blogs included and it was only the main topic in one of the discussion forums. Participant12 described a specific oral symptom, dry-mouth, and how to best address it. All authors mentioned oral care and the thematic

analysis process, as described by Braun and Clarke (2006), identified three main themes about this topic:

- Symptoms;
- Procedures;
- Emotions.

Symptoms

Oral symptoms, such as dry-mouth and difficulty in swallowing, were mentioned explicitly or implicitly in 15 of the 16 blogs and discussion forums. Dry-mouth was explicitly mentioned by participant1: *'...swabbing my father's mouth with a little sponge dipped in solution would help with dryness...'* and implicitly mentioned by participant3: *'They had provided sponges that we could use to moisten her lips and tongue...'*

The oral symptoms reported by most authors were dry-mouth, dry lips and difficulty in swallowing. In one of the discussion forums (11), which reported on the side-effects of chemotherapy and radiotherapy, other symptoms were described such as loss of taste sensation, mouth ulcers and mucositis. These were symptoms relatives could observe themselves.

'My brother noticed a few hours before he died that his mouth was dry and he held a cotton wool swab dipped in water to his mouth...' (10)

'...his mouth is totally dry and obviously very unpleasant...' (12)

Therefore, relatives could prepare for these symptoms. However, most authors were reacting to them.

'I would have watched for certain symptoms instead of reacting to them...' (8)

The oral symptoms palliative care patients experienced and that could be observed by their relatives, were often considered distressing to both patients and relatives. This was often an assumption on the part of the relatives. Fourteen of the 16 palliative care patients mentioned in the blogs and discussion forums were terminally-ill.

'All I could do was put some lip balm on his lips and pray that it would offer him some relief to the dryness of his lips and he would forget about his dry mouth.' (5)

'...we were anxious to keep him as comfortable as possible so continued to offer the swab dipped in water.' (10)

Only one author (6) did not mention oral symptoms. The oral care provided to her father was part of his *'morning cleaning'*. This was his routine daily care and no oral symptoms were reported:

'This entailed giving him a sponge bath and changing his diaper, emptying his colostomy bag, cleaning out his mouth with a sponge and water...'

Procedures

All authors reported oral care procedures. Except for one of the blogs (1), these were described mainly as techniques. Eleven authors described the use of a swab/sponge to clean and moisten the mouth:

'...swabbing my father's mouth with a little sponge dipped in solution...' (1).

In two blogs and one discussion forum, the authors reported using ice chips and/or frozen juice to moisten the mouth:

'...want to moisten their mouth, you can feed them tiny ice chips.' (2).

One blogger reported using lip balm to relief mouth dryness for her father. In one discussion forum, a named brand of chewy sweets is recommended to alleviate dry

mouth. Most descriptions and recommendations did not provide much detail about the oral care procedure itself.

One discussion forum (11) provided more detailed advice on oral care. This was a discussion forum started by the wife of a cancer patient, inquiring on how to best help her husband through chemotherapy and radiotherapy. The participants of this forum gave very specific advice on what to do regarding loss of taste sensation, painful mouth ulcers, difficulty in swallowing and mucositis.

'... I used Difflam anaesthetic mouthwash to numb the ulcers for long enough to eat. It has to be taken 20 minutes before a meal...' (11)

In one of the blogs (1) the oral care procedures provided were more than a technical act to address oral symptoms. These were described as being simple procedures that were part of the regulations of the hospice. However, oral care was delivered at irregular times and was even considered dangerous:

'The little sponge should be squeezed and most of the solution or water drained out of it, then the person who is unable to swallow (my father)... will not aspirate liquid which could kill him. I turned my back ... I saw another one pull the sponge from my father's mouth, dip it in the solution and reinsert it. My father began choking...' (1).

Emotions

When oral care procedures were described mainly as a technical act to address oral symptoms and as part of routine care, participants presented a neutral attitude and feelings towards them.

However, some authors explored their emotions in relation to oral care more extensively. Participant1 reported a general sense of anger towards the staff at the hospice. She described the oral care provided as being irregular, incorrect and even dangerous.

‘...sponge in a blue liquid, and heading towards my father’s open mouth...I told her to get away from my father and the nurse supervisor came in and quickly removed the evidence...’ (1)

Participant3 highlighted the revulsion and disgust felt by some of her family members when she was swabbing her grandmother’s mouth.

‘As I removed the sponge every other person in the room reacted with revulsion.’ (3)

In addition, she swabbed her grandmother’s mouth to appease her family, who felt they had to do something to make her more comfortable.

Participants 10 and 13 expressed worry, guilt and trauma. Participant10 was worried that her actions had caused her father unnecessary distress and there was guilt about this fact.

‘...we were anxious to keep him as comfortable as possible so continued to offer the swab dipped in water. The problem is that I can’t stop worrying about the fact that we might have caused him to choke.’ (10)

Participant13 described going through the trauma of witnessing their mother dying a painful death and feeling guilt about not having been able to do anything to help.

‘Like you, I found it so hard to be unable to do anything for her at all, because I was told not to even swab her mouth to moisten it...’ (13)

The emotions regarding oral care cannot be separated from the context in which these reports take place. Most palliative care patients mentioned are terminally-ill and the deaths of ten were recounted within the blogs and discussion forums.

2.5 Discussion

The objective of palliative care, including palliative oral care, is to provide relief from pain, stress and other symptoms (Kvalheim *et al.*, 2016). The aim is to improve quality-of-life for terminally-ill patients and their families (Wiseman, 2000).

It is reported that the majority of palliative care patients present a wide range of oral symptoms (Jobbins *et al.*, 1992; Kvalheim *et al.*, 2016; Saini *et al.*, 2009; Wiseman, 2000). Data from Norway suggests that 56% of patients receiving end-of-life care complained of dry-mouth, 49% complained of thirst and 74% of changes in eating habits (Kvalheim *et al.*, 2016). Dehydration is a common problem amongst these individuals.

Therefore, it is not surprising that most participants described oral symptoms such as: dry-mouth, dry lips and difficulty in swallowing. Oral diseases which can be symptomless and less easy to identify were not reported. However these findings are comparable to those by Rohr *et al.*, (2010). In their study, Rohr *et al.*, (2010), interviewed 14 terminally-ill patients about their experiences of oral discomfort and concluded dry-mouth was the most commonly reported oral problem.

All participants described an oral care procedure, albeit without much detail. These were mainly a technical act to address oral symptoms and provide comfort. When oral care was not provided this was in order to avoid causing stress to their loved one and was usually because they had been advised not to do so. It appears that generally oral care was provided in reaction to signs and symptoms rather than to pro-actively improve quality of life.

The last theme that emerged from the data analysis, emotions, is not one that is prioritised in the papers or documents found during the literature reviewed in

preparation for this study. The emotions described by the participants varied from anger, guilt, worry and trauma to a more neutral approach. When oral care was described as a technical act, participants did not report any positive or negative emotions. Some form of oral care was expected to happen and therefore this did not initiate an emotional response from the participants.

However, when there was an emotional response to oral care, this was a negative one. One participant described the incompetence of staff providing oral care and this led to anger and stress. The fact that staff did not seem to know what to do was thought to have caused discomfort, pain and harm to the patient. This inevitably led to the relative feeling the emotions described above.

Furthermore, when one of the participants swabbed her grandmother's mouth, other family members turned away or walked away expressing disgust, proving oral care is not seen as being easy or pleasant to perform for others. Indeed Couch *et al*, (2013) report similar findings in their study. They studied the oral care perceptions of paediatric palliative care nurses and described some of the barriers to providing mouth care, namely patient and/or family resistance.

Finally, some participants felt guilt specifically in relation to oral care. There was guilt because they perceived that the oral care they provided was not correct and was potentially harmful. There was guilt for not being able to provide oral care or for being told not to do so.

2.6 Limitations

Blogs involve an enormous commitment in terms of time and energy. Therefore, individuals that are terminally-ill and receive palliative care are very unlikely to be keeping a blog of their journey particularly in the latter stages of their illness. Hence, we relied on reports from relatives for this study, which is a limitation. The relatives' perspective and experience on oral care cannot be claimed to be that of the patients themselves. Relatives cannot speak for the patients and we also recognise that data was gathered in a context. It was not possible to assess the impact of context (for example, UK vs USA) and other factors such as time of reporting and emotional state of the participants.

In addition, as participants could not be probed, data collected may have less depth than for example data from interviews. Moreover, the potential to get people to explore subjects that are more sensitive for them may have been missed as well. The analysis of the three themes, identified by using Braun and Clarke's thematic analysis, could not be checked with the participants either. However, a second experienced reviewer on qualitative research reviewed the themes, sub-themes and data extracts. This ensured rigour.

Finally, the experiences of some participants were over-represented. This occurred as some participants wrote more about the topic of interest than others. Participants wrote about what was important to them rather than only about oral care. However, the themes were supported by the analysis across all participants.

2.7 Conclusion

Terminally-ill individuals often present a multitude of oral symptoms. This inevitably compromises their quality of life. Therefore, it is argued by HCPs that oral care should be included in the ongoing care plan of every palliative care patient. However, research on palliative oral care is scarce and the level of evidence underpinning it is weak. In addition, the perspective of patients and relatives has rarely been sought.

This study aimed to begin to address this gap. Oral care was not the main topic in any of the blogs and most of the discussion forums and data on oral care were scarce. It seems, however, that oral care for terminally-ill patients tends to be overlooked until the person's quality of life becomes noticeably compromised by the oral symptomatology.

It cannot be claimed that the findings of this study are generalisable. Nonetheless, they reflect the perspective of several individuals regarding the oral care provided to their terminally-ill relatives. This study did provide insight into a poorly researched area and will inform a future qualitative interview study.

CHAPTER 3: The oral care experiences of palliative care patients, their carers'/relatives' and HCPs': a qualitative systematic review.

This chapter is presented as a ready to submit manuscript. It describes and presents the findings of a qualitative systematic review of the literature on the oral care of palliative care patients. Following the study of blogs and discussion forums, the researcher went back to the literature and reviewed it in a systematic way, looking for answers to the research question stated in the introduction. In this qualitative review, oral care was explored from the perspective of palliative care patients and HCPs and the experiences of relatives and/or carers continued to be examined.

3.1 Introduction

There is a projected growth in demand for palliative care in England and Wales between 25% and 40% by 2040 (Etkind *et al.*, 2017). Similar estimates are expected for other high-income countries. The drive for more palliative care is due to a projected rise in deaths from chronic illnesses, people living longer and an increase in overall deaths. However, it is not clear how HCPs and services are to meet this rise in demand (Etkind *et al.*, 2017).

In addition to the expected increase in number of people needing palliative care, it is known that some of the most common symptoms these individuals experience are not being met adequately (NHS Scotland, 2014). Oral symptoms, such as dry-mouth or xerostomia, mucositis and candidiasis are amongst the most common symptoms palliative care patients experience (Kinley & Brennan, 2004; Kvalheim *et al.*, 2016; Milligan *et al.*, 2001; NICE, 2018). Moreover, oral symptoms can precipitate further life-threatening complications such as anorexia, malnutrition, cachexia and aspiration pneumonia (Lee *et al.*, 2001; Wiseman, 2000). Indeed, the number of decayed teeth, frequency of brushing and dependency on others for oral care are considered to be significantly associated with aspiration pneumonia (Langmore *et al.*, 2002; Langmore *et al.*, 1998).

Nevertheless, dental professionals do not seem to be playing an active role and be involved in the care of these individuals (Chen *et al.*, 2013a; Quinn, 2013; Saini *et al.*, 2009; Wiseman, 2006). Furthermore, research on the oral care of palliative care patients appears to be scarce (Bernardes Delgado *et al.*, 2018; Fitzgerald & Gallagher, 2018; Kvalheim *et al.*, 2016) and a systematic review of the literature on the oral care

experiences of palliative care patients, their relatives/carers and HCPs has not yet been conducted.

Aim and review question

The aim of this systematic review was to explore the oral care experiences of palliative care patients and of those who support or deliver oral care to these individuals, namely their relatives, carers and HCPs.

More specifically, this systematic review aimed to answer the following review questions:

- What are the oral care experiences of patients during palliative care?
- What are the experiences of those who provide oral care or support palliative care patients in their oral care, such as relatives, carers and HCPs?

3.2 Methods

Synthesis methodology

Conventional systematic reviews have demonstrated great benefits in synthesising evidence where the aim is to test theories (Dixon-Woods *et al.*, 2006). These tend to be aggregating reviews where findings from primary studies are added up to answer a review question (Gouch, Oliver & Thomas, 2012). These systematic reviews, traditionally, are conducted using primarily a quantitative approach (Methley *et al.*, 2014a). However, qualitative reviews are now regarded as a valuable and necessary type of research to answer health service research questions, such as investigating experiences of people with Multiple Sclerosis when accessing healthcare services

(Methley *et al.*, 2014b). There is a strong case for the potential qualitative research has in informing policy and practice (Thomas & Harden, 2008).

The aim of this systematic review was to explore the oral care experiences of palliative care patients, their relatives and/or carers and HCPs. This aim is aligned with the type of research described above and one that is better suited with a qualitative approach to data collection, analysis and synthesis.

Regarding the reviewer's ontological and epistemological positions these are aligned with critical realism, in which knowledge of reality is mediated by beliefs and perceptions (Barnett-Page & Thomas, 2009; Gough, Oliver & Thomas, 2012). Ontology refers to theories about the nature of reality or being and epistemology refers to nature of knowledge (Braun & Clarke, 2013; Gough, Oliver & Thomas, 2012). Critical realism is the term used for the integration of a realist ontological position with a constructivist epistemological position (Maxwell & Mittapalli, 2010). This means that during this review a standpoint was adopted in which it was argued there is a real world that exists independently of people's perceptions and constructions, i.e. realist ontology. However, people's understanding of this world is inevitably a construction from their own perspectives, i.e. constructivist epistemology. Critical realism asserts that there is a reality, however one can only partially know it (Braun & Clarke, 2006). Knowledge is subjective, socially-located and there are valid alternative accounts of any given phenomenon (Braun & Clarke, 2006; Maxwell & Mittapalli, 2010). Therefore, all theories about the world are grounded in a viewpoint and all knowledge is incomplete and fallible (Maxwell & Mittapalli, 2010).

Critical realism underpins some qualitative research using approaches such as thematic analysis, phenomenological analysis, grounded theory and discourse analysis (Braun &

Clarke, 2006). In addition, by integrating a realist ontological position with a constructivist epistemological position it retains realism while accepting constructivism. It is a pragmatic approach that is compatible with different methods (Maxwell & Mittapalli, 2010), including the method chosen for this review: thematic analysis.

Design

The reviewer conducted a qualitative systematic review which is reported adhering to the ENTREQ statement for reporting of synthesis of qualitative studies, as per Appendix 4 (Tong *et al.*, 2012). In addition, the protocol for this systematic review was registered with PROSPERO (registration number CRD42017071929) on 19th October 2017 as a mixed method systematic review. The qualitative methods and synthesis of the review findings are reported in this chapter.

The SPIDER tool (Cooke, Smith & Booth, 2012; Methley *et al.*, 2014a) was used to frame the research question and to structure the eligibility criteria:

S (Sample): adult palliative care patients;

PI (Phenomenon of Interest): oral care;

D (Design): not limited to a type of qualitative data collection or analysis;

E (Evaluation): experiences;

R (Research Type): primary, empirical, quantitative studies with open-ended questionnaires; qualitative studies; mixed-methods studies.

Approach to searching

The researcher developed a pre-planned comprehensive search strategy with the help of an information specialist. Despite the research question being framed using the SPIDER tool, the literature suggests that this tool can lead to a lower identification rate of

relevant qualitative studies (Methley *et al.*, 2014a). This is due to poor labelling and poor quality of indexing of qualitative research (Cooke, Smith & Booth, 2012; Methley *et al.*, 2014a).

Although the search was not driven by the imperative to locate all relevant studies, as found by Thomas and Harden (2008), the methods used to find qualitative data did not differ greatly from the ones used for a conventional systematic review. Hence the PICO tool was used to search several databases. This is also in line with what Methley *et al.* (2014a) suggested when comprehensiveness is a key factor to searching the literature.

Following a comprehensive search of a variety of databases, the reference lists of included papers were also searched.

Inclusion criteria

There were no limits applied regarding date of publication, setting and location. Studies exploring the oral care of adult palliative care patients using qualitative methodology such as focus groups, interviews and open-ended questionnaires were included. Articles were included if the main topic was oral care and there was some description of the phenomenon of interest. Papers that did not use qualitative methodology or only described oral symptoms were excluded. Pre-defined eligibility criteria are described in table2.

Table 2: Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
S: Sample	Adult palliative care patients.	Under 18 years of age patients.
PI: Phenomenon of interest	Oral care*, such as tooth brushing and moistening oral cavity (self-care or provided by relatives, carers, healthcare professionals and dental professionals); Professional oral care (dental professionals).	Papers in which the main topic is not oral care and/or oral health
D: Design	-	No exclusions regarding types of qualitative data collection or analysis
E: Evaluation	Experiences of oral care	Papers only describing oral symptoms; Papers that do not mention some form of oral care/mouth care experience.
R: Research type	Primary, empirical, quantitative studies with open-ended questionnaires; Qualitative studies; Mixed-methods studies.	Quantitative studies, including closed-ending questionnaires and cross-sectional methods; Non-empirical work, such as editorials and opinion papers; Narrative reviews.
Other	Own residence, care-home, nursing-home, hospital or hospice. Papers written in English.	No exclusions regarding setting. Non-English language papers.

Oral care* measures for palliative care patients include, but are not limited to:

- Oral hygiene, such as tooth brushing, cleansing of dentures, rinsing the mouth, removing coatings, debris and plaque from oral mucosa and lips (NHS Scotland, 2014);
- Keeping the mouth and lips moist and intact (NHS Scotland, 2014);
- Management of painful mucositis (Milligan *et al.*, 2001);
- Management of xerostomia, fungal infections and oral pain (Milligan *et al.*, 2001)

Data sources and search strategy

An electronic search of Embase and MEDLINE (using OVID interface), of DOSS and AMED (using EBSCO interface) and PsycINFO (NHS HDAS) was completed on the 31st of August 2017 and updated on the 2nd of November 2019. The search history for Embase and MEDLINE are listed in Appendix5.

The database searches generated a total of 3919 records which were imported into Endnote X8. One additional record was generated through citation searching. Figure2 presents a flow diagram of the search and selection processes. De-duplication produced a total of 2118 records. These were uploaded to Rayyan QCRI, a systematic review free internet application (Ouzzani *et al.*, 2016), and titles and abstracts were examined independently by the reviewers MBD and AP against pre-defined eligibility criteria (Table 2). The screening process resulted in the exclusion of 2057 records. MBD and AP read the full text of 63records independently. There was disagreement between MBD and AP regarding one record. A third reviewer (JML) was consulted and four articles were selected for quality appraisal. The reasons for excluding articles at the full-text stage can be found in Appendix6.

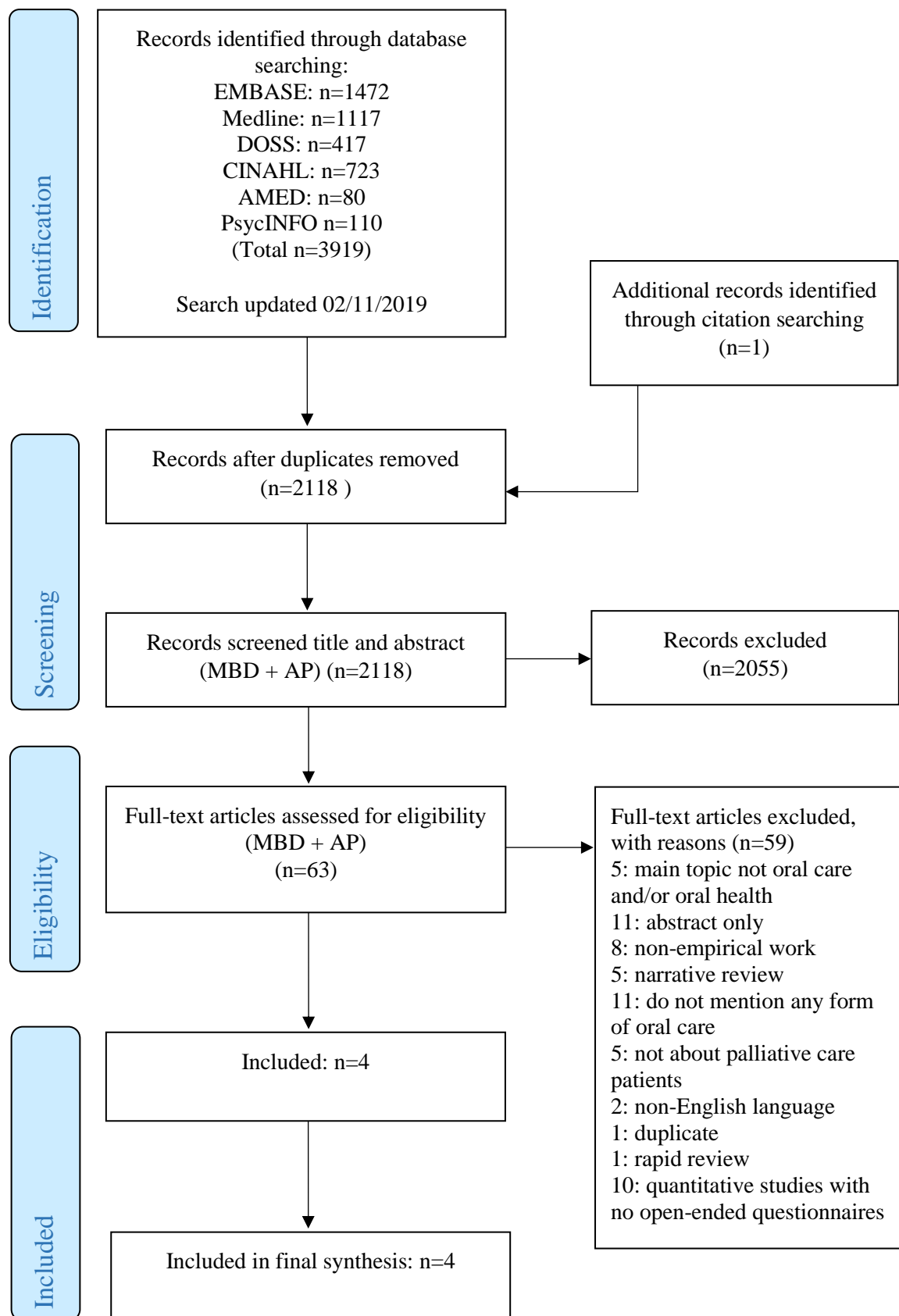


Figure 2: Selection process of articles - adapted version of the PRISMA 2009 flow diagram (Liberati *et al.*, 2009; Moher *et al.*, 2009)

Rationale for appraisal and process

In order to avoid drawing unreliable conclusions, the quality of qualitative studies needs to be assessed (Thomas & Harden, 2008). However, it is acknowledged there is little empirical evidence on which to base decisions regarding the exclusion of studies on their quality appraisal (Thomas & Harden, 2008). Therefore, it was decided to assess the quality but also that if the number of high-quality papers was limited, studies with low quality would be considered to be included. Nevertheless, in this review it was observed that the included studies with higher methodological quality contributed more to the findings than Milligan *et al.* (2001), which scored the lowest.

The quality appraisal was conducted by two researchers independently (MBD and JML), who employed the Critical Appraisal Skills Programme (CASP) Qualitative checklist (CASP., 2018). An open dialogue was maintained between the two researchers and disagreements were resolved through discussion during a meeting.

Other quality assessment tools were considered, such as the Joanna Briggs Institute's Checklist for Qualitative Research (JBI-CQR). Both the CASP and the JBI-CQR are 10-item checklists to appraise qualitative evidence and present similarities (Hannes, Lockwood & Pearson, 2010). Nevertheless, it was agreed amongst the researchers to employ the CASP Qualitative checklist. The CASP not only assesses the value and implications of research to other settings, but it is also a more user-friendly tool than the JBI-CQR (Hannes, Lockwood & Pearson, 2010).

Data synthesis

In this review data from the patients', carers/relatives' and HCPs' perspectives regarding the oral care of palliative care patients were analysed. Equal value was placed

onto these different perspectives and experiences. Critical realism accepts the possibility of alternative valid accounts of any phenomenon (Maxwell & Mittapalli, 2010).

The method chosen to analyse these perspectives and experiences was thematic analysis. This is a flexible method that allowed the identification of themes and patterns across the dataset. It also allowed the researcher to analyse the data according to the three different perspectives and then compare and contrast the themes generated from patients, relatives/carers and HCPs.

The four papers included were uploaded into a computer-aided qualitative analysis software: NVivo12 (Bazeley & Jackson, 2013). Each paper was analysed according to the participants' and authors' perspectives separately. Only the relevant sections in the papers were analysed i.e. qualitative data on oral care experiences.

The six steps described by Braun and Clarke (2006) were followed to generate codes and themes:

- The researcher read and re-read the four papers included, in their entirety and subsequently focused only on the relevant sections (1:familiarisation with the data);
- These relevant sections were then extracted, and initial codes were produced. These sections retained enough text to guarantee understanding of meaning (2:generating initial codes);
- The initial codes were subsequently sorted into potential themes and sub-themes (3:searching for themes);
- The candidate themes and sub-themes were then refined and checked against the coded data extracts (4:reviewing themes);

- The researcher re-read the entire data set and sought to identify the essence of what each theme was about. A second reviewer reviewed the themes, sub-themes and data extracts. Further refinement of themes and sub-themes took place during discussion between the two reviewers. Finally, the analysis was written, and the story of the data was told (5: defining and naming themes 6: producing the report).

Although the six steps were described above in a linear way, the analysis, as defended by Braun and Clarke (2006), was more a recursive process. There was a constant moving back and forward throughout the stages. In addition, two researchers (MBD and JML) collaborated in the analysis to ensure rigour. Thematic analysis enabled the reviewers to find important themes across the three groups and it also showed where conflict and gaps existed.

3.3 Results

Four papers were included in the synthesis of this qualitative systematic review as per the PRISMA diagram in Figure2 summarising the selection process.

Appraisal results

The methodological quality of the four studies included was appraised, as stated above, by two researchers independently, using the CASP Qualitative checklist (CASP., 2018).

This tool enables researchers to assess how valid the studies' results are by asking the first six questions (Table3). None of the studies included met all the six items pertaining to the results' validity. Bernardes Delgado *et al.* (2018) and Rohr *et al.*, (2010) met the first five items but in neither study did the authors consider their relationship with

participants and how their role could lead to potential for bias and influence (Q6). It is true that with the study of blogs and discussions forums (Bernardes Delgado *et al.*, 2018) there was no interaction between researchers and participants as only secondary data were analysed. However, Rohr *et al.*, (2010) conducted interviews with palliative care patients. The other two studies (Croyere *et al.*, 2012; Milligan *et al.*, 2001) only met two items and one item respectively out of the first six questions in the checklist. One could question the validity of the results presented in these two articles.

Questions seven to nine relate to what the actual findings of the studies are (Table 3). Only Bernardes Delgado *et al.*, (2018) met all three items. Two of the studies (Croyere *et al.*, 2012; Rohr, Adams & Young, 2010) it was not possible to ascertain how rigorous the analysis of the findings had been (Q8) and with Milligan *et al.*, (2001) it was concluded that the analysis had not been rigorous (Q8).

Finally, the last question in the CASP Qualitative checklist asks about the impact of the research and how valuable it is. Two of the included articles (Croyere *et al.*, 2012; Rohr, Adams & Young, 2010) demonstrated how the results could help locally. However it was not possible to assess this item conclusively in the other two papers (Bernardes Delgado *et al.*, 2018; Milligan *et al.*, 2001).

The methodological quality assessment leads to the conclusion that none of the studies included met all 10-items of the checklist used. It could be argued that one or indeed two of the studies should be excluded from the analysis. However, there is a paucity of research on the phenomenon of interest i.e. the oral care experiences of palliative care patients, their carers'/relatives' and HCPs. Therefore, it was considered that the relevance of data should take precedence over the quality of the research being reported and all four papers were included in the qualitative synthesis.

Table 3: Assessment of methodological quality										
CASP Qualitative checklist	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Bernardes Delgado <i>et al.</i> (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	CT
Croyere <i>et al.</i> (2012)	Y	Y	CT	CT	CT	N	Y	CT	Y	Y
Milligan <i>et al.</i> (2001)	Y	CT	CT	CT	CT	N	Y	N	Y	CT
Rohr <i>et al.</i> , (2010)	Y	Y	Y	Y	Y	N	Y	CT	Y	Y
<p>Q1-Q6: Are the results valid? Q1: Was there a clear statement of the aims of the research? Q2: Is a qualitative methodology appropriate? Q3: Was the research design appropriate to address the aims of the research? Q4: Was the recruitment strategy appropriate to the aims of the research? Q5: Was the data collected in a way that addressed the research issue? Q6: Has the relationship between researcher and participants been adequately considered?</p> <p>Q7-Q9: What are the results? Q7: Have ethical issues been taken into consideration? Q8: Was data analysis sufficiently rigorous? Q9: Is there a clear statement of findings?</p> <p>Q10: Will the results help locally? How valuable is the research?</p> <p>Y: yes; N: no; CT: can't tell</p>										

Study characteristics

The articles included in this review were published between 2001 and 2018. The participants were palliative care patients (Milligan *et al.*, 2001; Rohr, Adams & Young, 2010), HCPs (Croyere *et al.*, 2012; Milligan *et al.*, 2001) and relatives of palliative care patients, who wrote about their own experiences and the experiences of their relatives (Bernardes Delgado *et al.*, 2018).

In relation to patients' diagnosis, one study referred to patients with a diagnosis of respiratory problems and neuro-oncology pathologies (Croyere *et al.*, 2012) and another

referred to patients with a diagnosis of advanced cancer (Milligan *et al.*, 2001). Rohr *et al.*, (2010) did not state the diagnosis of the study's participants. Bernardes Delgado *et al.*, (2018) reported on a table with demographic data some diagnoses: Alzheimer's, cancer, pancreatic cancer and throat cancer. The diagnosis was not mentioned for all the blogs and discussion forums included. Palliative care patients were only participants of the studies reported by Milligan *et al.*, (2001) and Rohr *et al.*, (2010). In Bernardes Delgado *et al.*, (2018) the participants were relatives and in Croyere *et al.*, (2012) the participants were HCPs.

Blogs and discussion forums were written by relatives in the USA, UK and Canada (Bernardes Delgado *et al.*, 2018). The other three studies included took place in:

- Five surgical and rehabilitation hospital units in France (Croyere *et al.*, 2012);
- Hospices and hospice units in the UK (Milligan *et al.*, 2001);
- Palliative care service in a hospital in Australia (Rohr, Adams & Young, 2010).

Two of the included studies are qualitative studies and the authors employed thematic analysis to analyse the data from blogs and discussion forums (Bernardes Delgado *et al.*, 2018) and semi-structured interviews (Rohr, Adams & Young, 2010). The remaining two studies are mixed-methods studies that used focus groups and questionnaires (Croyere *et al.*, 2012) and open-ended questionnaires and visual/microbiological assessments (Milligan *et al.*, 2001) to collect data. Croyere *et al.*, (2012) stated that the focus groups were analysed according to the theory of self-efficacy and it was not possible to ascertain the methodology used to analyse the data from the open-ended questionnaires in the study by Milligan *et al.*, (2001).

The phenomena of interest described in the studies included were the oral care experiences of palliative care patients (Bernardes Delgado *et al.*, 2018; Milligan *et al.*,

2001; Rohr, Adams & Young, 2010) and the social representation of healthcare professionals regarding the oral care of palliative care patients (Croyere *et al.*, 2012). More specifically the oral care experiences of palliative care patients from the perspective of their relatives (Bernardes Delgado *et al.*, 2018), palliative care patients' experiences of oral pain and xerostomia after the implementation of an oral health protocol (Milligan *et al.*, 2001) and the oral discomfort experiences of palliative care patients (Rohr, Adams & Young, 2010).

The characteristics of the included studies are summarised in Table4.

Table 4: Characteristics of included studies

Included studies	Methodology	Phenomenon of interest	Participants and sample	Setting	Key findings
Bernardes Delgado <i>et al.</i>, 2018	Qualitative study: Thematic analysis.	Oral care experiences of palliative care patients, from the perspective of their relatives and/or carers.	<p>Relatives of palliative care patients.</p> <p>Not possible to ascertain diagnosis of all palliative care patients. It included patients with Alzheimer's and cancer.</p> <p>8 authors of blogs and 8 contributors to discussion forums 13 females, 2 males and 1 not possible to identify gender</p>	USA, UK and Canada (blogs and discussion forums).	<p>Oral care was not the main topic in any of the blogs and most of the discussion forums.</p> <p>Oral care tends to be over-looked until the person's quality of life becomes noticeably compromised by the oral symptomatology.</p>
Croyere <i>et al.</i>, 2012	<p>Mixed-methods: Focus groups and questionnaire.</p> <p>Analysis according to the theory of self-efficacy.</p>	The social representation that nurses and healthcare assistants share regarding oral care for patients in a non-specialist palliative care setting.	<p>Nurses and healthcare assistants providing non-specialist palliative care.</p> <p>84 completed questionnaires (84 nurses and healthcare assistants) 38 participated in focus group (12 nurses and 26 healthcare assistants)</p> <p>Palliative care patients with diagnosis of respiratory problems and neuro-oncology pathologies.</p>	France Five surgical and rehabilitation hospital units.	<p>Staff reports confusion regarding the choice of products and resources.</p> <p>Oral care for palliative care patients was part of their role.</p>
Milligan <i>et al.</i>, 2001	<p>Mixed methods: Survey, visual assessment, interviews and microbiological assessment.</p> <p>Analysis not stated.</p>	To monitor prevalence of oral problems among patients admitted to hospices and assess changes in oral health with implementation of oral care according to a protocol.	<p>Managers and patients with advanced cancer</p> <p>23 patients took part in the interviews.</p>	UK. Hospices and hospice units.	Oral care based on the protocol, if delivered consistently, resulted in improvements in oral cleanliness and patients' perceptions of oral comfort.

Rohr, Adams and Young (2010)	Qualitative study: Semi-structured interviews. Thematic analysis	Experiences of terminally-ill patients regarding oral discomfort.	Terminally-ill patients 14 patients. not possible to ascertain diagnosis of palliative care patients.	Australia. Palliative care service (hospital).	All participants described a range of oral problems that impacted on their quality of life. There was either a casual approach or an absence of oral assessments.
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3.4 Review findings

The thematic analysis identified three themes regarding the oral care experiences of palliative care patients, relatives/carers and HCPs: ‘performing oral care’, ‘effects on oral health’ and ‘challenges in palliative care’. These main categories can be broadly described as something that is done by and to participants i.e. ‘performing oral care’, the impact of oral symptoms i.e. ‘effects on oral health’ and something that adds difficulties to the experience of oral care i.e. ‘challenges in palliative care’.

In addition, within each theme further three sub-themes were identified:

- ‘Performing oral care’: ‘oral hygiene’, ‘promoting comfort’ and ‘timing of oral care’;
- ‘Effects on oral health’: ‘oral symptoms’, ‘wider impact of oral symptoms’ and ‘improving oral symptomatology’;
- ‘Challenges in palliative care’: ‘wider impact of oral care’; ‘barriers to oral care’ and ‘overcoming challenges in oral care’.

Table5 presents the themes and sub-themes identified in addition to representative data extracts from the four papers included. Furthermore, the authors’ comments and contribution to themes and sub-themes are presented in a separate column.

Each theme and sub-theme are reported with further detail in the sections below.

Table 5: Contribution of studies to themes and sub-themes

THEMES	SUB-THEMES	CONTRIBUTION OF STUDIES	CONTRIBUTION OF STUDIES
		Study participants	Authors' comments
Performing oral care	Oral hygiene	<p><i>'swabbing my father's mouth with a little sponge dipped in solution'</i> P1, p3</p> <p><i>'You know when your mouth is clean.'</i> P3, p424</p> <p><i>'I have my own teeth... I clean my teeth a lot more than what I used to.'</i> P4, p442</p> <p><i>'At home... I was washing my teeth a lot. [In here] oh, well when they come to wash you, the first thing I do is clean my teeth... And then the same at night, when they come to put the lights out and turn me over. I, I make sure I've cleaned my teeth. Yes [I do that in my bed]. Like, I manage the toothbrush.'</i> P4, p442</p>	<p><i>'The predominance of hygiene and comfort over the other themes in the results was explored with the help of the focus groups. One explanation given was that hygiene is seen as a principal nursing role and that for health-care assistants tooth brushing is seen as part of routine daily care and therefore it is their job to assist with it. According to the focus group the idea of freshness was associated with hygiene, probably owing to the participants' personal use of toothpaste and tooth brushing.'</i> P2, p437, 438</p> <p><i>'The present study identified a concern for both cleanliness and comfort'</i> P2, p439</p> <p><i>'Care based on this protocol, when consistently delivered, resulted in measurable improvements in oral cleanliness and patients' perceptions of oral comfort. This is despite the fact that the care provided is neither complicated nor expensive.'</i> P3, p425</p>
	Promoting comfort	<p><i>'All I could do was put some lip balm on his lips and pray that it would offer him some relief to the dryness of his lips and he would forget about his dry mouth'</i> P1, p3</p> <p><i>'I used Difflam anaesthetic mouthwash to numb the ulcers for long enough to eat. It has to be taken 20 minutes before a meal.'</i> P1, p3</p> <p><i>'if the mouth is clean the patient is comfortable and therefore presentable for his or her family. Other prerequisites for comfort are the absence of a dry mouth and the absence of pain associated with mouth lesions.'</i> P2, pp438</p> <p><i>'My mouth feels better in every way...'</i> P3, p424</p>	<p><i>'All participants described an oral care procedure, albeit without much detail. These were mainly a technical act to address oral symptoms and provide comfort. When oral care was not provided this was in order to avoid causing stress to their loved one and was usually because they had been advised not to so. It appears that generally oral care was provided in reaction to signs and symptoms rather than to pro-actively improve quality of life.'</i> P1, p4</p> <p><i>'The present study identified a concern for both cleanliness and comfort'</i> P2, p439</p>

			<p><i>'Care based on this protocol, when consistently delivered, resulted in measurable improvements in oral cleanliness and patients' perceptions of oral comfort. This is despite the fact that the care provided is neither complicated nor expensive.'</i> P3, p425</p>
	Timing of oral care	<p><i>'At home... I was washing my teeth a lot. [In here] oh, well when they come to wash you, the first thing I do is clean my teeth... And then the same at night, when they come to put the lights out and turn me over. I, I make sure I've cleaned my teeth. Yes [I do that in my bed]. Like, I manage the toothbrush.'</i> P4, p442</p>	<p><i>'the health-care assistants considered that oral health care should take place systematically during each general hygiene care, rather than following meals or at a time of patient choice...the nurses considered that oral care should be performed when they think it is necessary...it seems that proper oral health should indeed not be automatic but rather a question of thoughtful organisation'</i> P2, p439</p>
Effects on oral health	Oral symptoms	<p><i>'swabbing my father's mouth with a little sponge dipped in solution would help with dryness'</i> P1, p3</p> <p><i>'They had provided sponges that we could use to moisten her lips and tongue'</i> P1, p3</p> <p><i>'want to moisten their mouth, you can feed them tiny ice chips'</i> P1, p3</p> <p><i>'My brother noticed a few hours before he died that his mouth was dry and he held a cotton wool swab dipped in water to his mouth'</i> P1, p3</p> <p><i>'his mouth is totally dry and obviously very unpleasant'</i> P1, p3</p> <p><i>'The soreness has gone.'</i> P3, p424</p> <p><i>'I can taste better.'</i> P3, p424</p> <p><i>'My mouth feels better in every way...'</i> P3, p424</p> <p><i>'My mouth feels as though I have burnt it.'</i> P3, p425</p> <p><i>'Over the years I've had [dry mouth] ... nothing like the severity of this [laughs]... I get a little bit of dry mouth, but absolutely nothing like this. This is just, um, full out of control [laughs]'</i> P4, p440</p> <p><i>'Ah very bad dryness... since I've been sick... all I want is an undry mouth'</i> P4, p440</p>	<p><i>'it is not surprising that most participants described oral symptoms such as dry mouth, dry lips and difficulty in swallowing. Oral diseases which can be symptomless and less easy to identify were not reported.'</i> P1, p4</p> <p><i>'Patients on admission consistently reported that their mouths were dry or painful'</i> P3, p425</p> <p><i>'One man who was thought by previous carers to be withdrawn proved, on questioning, to be avoiding conversation simply because he found speaking too painful.'</i> P3, p425</p> <p><i>'Dry mouth extending from the lips to the throat was common among the oral problems described by patients. The degree of severity of dry mouth ranged from 'manageable' to 'out of control''</i> P4, p440</p> <p><i>'Other oral problems experienced included mucosal ulceration, thrush and loose and ill-fitting dentures'</i> P4, p440</p> <p><i>'The impact of the effects of oral discomfort encompassed many aspects of the lives of the participants including loss of enjoyment of food, loss of appetite, loss of weight and swallowing difficulties. Such consequences led to patients' making adjustments to their eating habits such as eating smaller meals, opting for softer foods and eating less frequently. At times oral dryness also meant speech was difficult, with participants describing choking sensation or slurring of speech.'</i> P4, p440</p>

		<p><i>'Dryness it's still about the same. Right down to my lips. They break out, but they're dry. But there's no moisture in my mouth at all' P4, p440</i></p> <p><i>'I have to wake up ten times a night to have a sip of water' P4, p440</i></p> <p><i>'But I had a lot of problems with ulcers, inside my mouth... and a lot of thrush right on top of the tongue, and the whole mouth was... very sore... approaching 3 months now, although it's been under control now for the last month' P4, p440</i></p> <p><i>'When the thrush was happening... I got the very unpleasant taste in my mouth... Well I'm not eating very well anywa'' P4, p440</i></p> <p><i>'It is very harsh and dry. Very dry, the mouth. Very dry. All right. And I have no appetite.' P4, p441</i></p> <p><i>'I slur everything... It makes you feel a bit stupid because you're slurring away there...I know my mouth's sticking together, that's why. And my tongue's stuck to my plates.' P4, p441</i></p> <p><i>'I have problems because I can't talk and I get sort of like, choking me. Some days, it's not too bad, I can talk a bit.' P4, p441</i></p> <p><i>'I had this big white fungus growing and all these ulcers... Ahh, it was just a continual battle to try and keep my mouth from getting that sore that I couldn't eat.' P4, p441</i></p>	<p><i>'Participant reports of physical problems of mucosal ulceration and infection, and especially recurrent and persistent oral dryness...' P4, p443</i></p>
	Wider impact of oral symptoms	<p><i>'You have no taste... And that's what makes me so cross, because taste to me is a lot... what's the use of bloody having it? Let's face it, if I can't, if I can't taste food I won't eat.' P4, p441, 442</i></p> <p><i>'My mouth is very dry, sometimes my mouth gets stuck, I've got a job to speak clearly, I sip water to be able to say anything... seems to have gone on forever... a bit short tempered... with trying to repeat yourself [Interviewer: "so you find it a bit frustrating?"] yeh, because it's there all the time.' P4, p442</i></p> <p><i>'...I had one [ulcer] on my tongue and one inside my mouth there you know... you'd mash it [food] up, but it was very annoying, to try to eat you know.' P4, p442</i></p>	<p><i>'As well as dealing with physical discomfort, most participants described their 'frustration' at dealing with oral problems and associated effects.' P4, p441</i></p> <p><i>'The most common social discomfort for participants stemmed from difficulties in communication. Speech difficulties led participants to feel embarrassed when stumbling over words.' P4, p442</i></p> <p><i>'Another experience common to many interviewees was the social impact of being unable to enjoy and share meals with friends and family. Painful mouths and/or the necessity for mashed foods limited social outings and participation at special occasions, such as Christmas dinner.' P4, p442</i></p>

		<p><i>'Well I think it's the same thing, my wife can't understand me half the time... but eh it's irritating when I've got to try repeating yourself... because I can't get the words out, yeh yeh.'</i> P4, p442</p> <p><i>'And also, I can be conscious about a smell coming out of my mouth... I clean it, I clean it of course... well I don't know if there's a smell. I can't smell myself.'</i> P4, p442</p>	<p><i>'... the current analysis reveals that oral health difficulties more generally significantly hinders patients' daily living and quality of life.'</i> P4, p443</p> <p><i>'The range of oral problems endured by participants affected social and emotional aspects of living.'</i> P4, p443</p>
	Improving oral symptomology	<p><i>'All those mouthwashes really make a difference.'</i> P3, p424</p> <p><i>'Your mouthwashes worked last time.'</i> P3, p425</p> <p><i>'One of your orange mouthwashes will help.'</i> P3, p425</p> <p><i>'My mouth is very, very dry, sometimes my mouth gets stuck, I've a job to speak clearly, I sip some water to be able to say anything... my voice will come louder...'</i> P4, p442</p> <p><i>'... to have a conversation with somebody, I only needed 2-3 minutes and my mouth was like a piece of parchment. It just would turn to parchment, and that's why that is the greatest thing that was ever invented (bottle of water) just wet my mouth... and continue for another couple of minutes and that's how I got through, through each day.'</i> P4, p442</p> <p><i>'... my mouth will stick to my teeth, and I can't open it till I have a, a drink and, and... oh [in frustration] ... Artificial saliva, yes. [It helps] only for a little while. Not for very long... oh I'd say only around about ten minutes, and then I have to have a drink of water. The water seems to be best.'</i> P4, p443</p> <p><i>'Nothing helps. I tried honey, and a cup of tea, and chamomile tea. It doesn't help. I tried all kind of lollies. It doesn't help...'</i> P4, p443</p>	<p><i>'Several comments from patients who had already experienced mouth care at Accord revealed that they remembered the beneficial effects'</i> P3, p425 (citations from patients mentioning mouthwashes follow this statement by the authors)</p> <p><i>'In response to dry mouth, all participants reported increasing their daily fluid intake, with a particular preference for water, needing to be readily available for quick consumption.'</i> P4, p442</p> <p><i>'Mouthwash was used by participants for remedial effect for dry mouth, ulcers and thrush, although its effect was limited when problems were severe and long lasting. The antifungal treatment was effective when introduced early but was more commonly used for much longer periods of time. A number of interviewees had tried saliva, with varying degrees of success...'</i> P4, p442, 443</p> <p><i>'Sugar-free gum, lollies, herbal teas and honey were remedies tried by some respondents with little or no success.'</i> P4, p443</p>
Challenges in palliative care	Wider impact of oral care	<p><i>'As I removed the sponge every other person in the room reacted with revulsion'</i> P1, p4</p> <p><i>'we were anxious to keep him as comfortable as possible so continued to offer the swab dipped in water. The problem is that I can't stop</i></p>	<p><i>'The emotions described by the participants varied from anger, guilt, worry, and trauma to a more neutral approach. When oral care was described as a technical act, participants did not report any positive or negative emotions. Some form of oral care was expected to happen and therefore this did not initiate an emotional response</i></p>

	<p>worrying about the fact that we might have caused him to choke.' P1, p4</p> <p>'Like you, I found it so hard to be unable to do anything for her at all, because I was told not to even swab her mouth to moisten it' P1, p4</p> <p>'participants, who reported that it violates the personal space of both parties and generates feelings of disgust about bad breath. The nursing staff also felt that these unpleasant feelings were reciprocated by the patients. The participants reported that they would not like to receive oral care but they would also not like not to receive it. They felt there is little reward in carrying out mouth care as it needs to be repeated frequently.' P2, p438, 439</p> <p>'It's [staff assistance with oral care] humiliating... I'm so, I like to be independent... I'm a very independent person...' P4, p442</p>	<p>from participants. However, when there was an emotional response to oral care, this was a negative one. One participant described the incompetence of staff providing oral care and this led to anger and stress. The fact that staff did not seem to know what to do was thought to have caused discomfort, pain and harm to the patient. This inevitably led to the relative feeling the emotions described above. Furthermore, when one of the participants swabbed her grandmother's mouth, other family members turned away or walked away expressing disgust, proving oral care is not seen as being easy or pleasant to perform for others.' P1, p4</p> <p>'Finally some participants felt guilt specifically in relation to oral care. There was guilt because they perceived that the oral care they provided was not correct and was potentially harmful. There was guilt for not being able to provide oral care or being told not to do so.' P1, p4</p> <p>'There was an initial expectation that the participants would report resistance to carrying out oral care, but instead the focus group showed that they considered it as much a part of their job as any other aspect of patient care. They did not consider oral care to be more unpleasant than some other aspects of their job, such as dealing with vomiting, faecal secretion, and expectoration. Questioning the possible unpleasantness felt by caregivers in their daily job may devalue all of the care carried out in close proximity to patients' bodies.' P2, p439</p> <p>'psychosocial functions of the mouth and positive self-image are also absent from the consideration of caregivers' P2, p439</p>
Barriers to oral care	<p>'The little sponge should be squeezed and most of the solution or water drained out of it, then the person who is unable to swallow (my father)... will not aspirate liquid which could kill him. I turned my back... I saw another one pull the sponge from my father's mouth, dip it in the solution and reinsert it. My father began choking...' P1, p3</p> <p>'sponge in a blue liquid, and heading towards my father's open mouth... I told her to get away from my father and the nurse supervisor came in and quickly removed the evidence' P1, p4</p>	<p>'The objectives of oral care and its adaption to individual patients needs are rarely referred to.' P2, p439</p> <p>'psychosocial functions of the mouth and positive self-image are also absent from the consideration of caregivers' P2, p439</p> <p>'While most participants administered their own oral care, tiredness and fatigue made the oral care regimen 'more tedious'' P4, p442</p>

		<p><i>'There was confusion over the choice of products and resources. This confusion was related to different recommendations given by the mobile palliative care teams, to the variety of medical prescriptions, and to changes in the guidelines, which led to participants not knowing whether they were current or pertinent. Other points of confusion were due to organisational and logistical factors, such as availability of resources and products constantly changing, for various reasons. The cost of different products could be an issue, as could changing recommendations and the need to test new resources like soft toothbrushes. The participants reported that they ultimately provide the oral care they think is appropriate with the resources they are comfortable with.'</i> P2, p438</p> <p><i>'in the focus groups, participants who indicated that patients sometimes refuse oral health care explained that these refusals were often due to patients finding the care painful and/or unpleasant because of neurological problems, or that they were a means of expressing distress'</i> P2, pp438</p> <p><i>'No-one has looked in my mouth. The outreach nurses come, they say the same thing – just wash it out.'</i> P4, p443</p> <p><i>'Ah, no-one's actually come over and gone 'ahhh', you know. They've been sitting on that side of the table I've been sitting on this side of the table.'</i> P4, p443</p>	<p><i>'Solutions did not seem to be readily available for those with ill-fitting or problematic dentures: only two participants mentioned involvement with their dentist in relation to their oral problems, whilst another participant, despite repeated presentations to a dental clinic, was placed on a 2-year waiting list for lower denture replacement.'</i> P4, p442</p> <p><i>'Participants tended to stress they 'mentioned' their dry mouth, rather than 'reported' the condition. The causes for dry mouth as given by health professionals such as 'after-effect of medication', or an 'age-related condition', seemed to reinforce to participants that the issue was not serious enough to pursue in its own right. Even when oral conditions persisted for extended periods of time, the ongoing examination of the mouth was minimal and sometimes only involved discussions around use and effectiveness of mouthwashes and/or antifungal preparations. Overall, the general impression to patients was that it was 'pointless' for professionals to look inside the mouth 'as there was nothing to see' and little the health staff could do to eliminate or ease their condition.'</i> P4, p443</p> <p><i>'From the perspective of the terminally ill participants, despite the extent and ongoing nature of oral difficulties encountered a deficit was noted, of thorough and structured assessment of interviewees' mouths by health professionals.'</i> P4, p443</p>
	Overcoming challenges in oral care		<p><i>'The analysis of the focus group responses found that there are issues that need to be addressed in order to reinforce caregivers' feelings of effectiveness in carrying out oral care for patients in palliative care. Addressing these practical points can take different forms, such as exercises within and outside the clinical setting (e.g. role play of a patient refusing oral care), identifying appropriate resources and their correct use, etc. During handover, discussions can take place about the appropriate moment for oral care for both the caregiver and the patient. A caregiver who feels at ease carrying out oral care can accompany another who feels uncomfortable. Also, explicit positive feedback can be elicited from patients, families, clinical specialists, managers, and other stakeholders.'</i> P2, p439</p>

			<p><i>'Focus groups involving oral caregivers showed that it is necessary for caregivers to feel that they and their colleagues are successful in carrying out oral care and to witness a positive outcome in order to feel convinced that good oral care is necessary.'</i> P2, p440</p> <p><i>'The results of this study are supportive of oral care for the terminally ill patient being raised to a clinical priority in hospice, acute hospital, and palliative community outreach settings to improve standards of professional holistic palliative care.'</i> P4, p444</p>
<p>Studies: P1 – Bernardes Delgado <i>et al.</i> (2018); P2 – Croyere <i>et al.</i> (2012); P3 –Milligan <i>et al.</i> (2001); P4 – Rohr, Adams and Young (2010)</p> <p>p – page number</p>			

Performing oral care

The act of ‘performing oral care’ is a theme that palliative care patients, relatives and HCPs contributed to. This act had the concepts of cleanliness and comfort as its justification and goal i.e. the sub-themes ‘oral hygiene’ and ‘promoting comfort’ respectively. Palliative care patients, relatives and HCPs described brushing teeth, swabbing mouths, applying lip balms and using mouthwashes in order to keep the oral cavity clean, moist and ultimately comfortable and pain-free.

‘I used Difflam anaesthetic mouthwash to numb the ulcers for long enough to eat. It has to be taken 20 minutes before a meal.’ P1, p3

There is also the perception amongst care givers that a clean mouth is not only comfortable to the patient but also more presentable to others. This is stated by healthcare professionals.

‘if the mouth is clean the patient is comfortable and therefore presentable for his or her family. Other prerequisites for comfort are the absence of a dry mouth and the absence of pain associated with mouth lesions’ P2, p438

The ‘timing to perform oral care’, the third sub-theme, is described by palliative care patients only. There is a change in routine from when this patient was at home and went to a palliative care unit. Not only was the patient washing his/her teeth more often at home, but since leaving home is performing oral care in bed. There was a change in routine and setting.

‘At home... I was washing my teeth a lot. [In here] oh, well when they come to wash you, the first thing I do is clean my teeth... And then the same at night, when they come to put the lights out and turn me over. I, I make sure I’ve cleaned my teeth. Yes [I do that in my bed]. Like, I manage the toothbrush.’ P4, p442

The authors of three out of the four studies (Bernardes Delgado *et al.*, 2018; Croyere *et al.*, 2012; Milligan *et al.*, 2001) also contributed to this theme and to all three sub-themes. The authors provided an explanation as to why hygiene and comfort were so important to HCPs and how oral hygiene contributed directly to comfort.

'The predominance of hygiene and comfort over the other themes in the results was explored with the help of the focus groups. One explanation given was that hygiene is seen as a principal nursing role and that for health-care assistants tooth brushing is seen as part of routine daily care and therefore it is their job to assist with it. According to the focus group the idea of freshness was associated with hygiene, probably owing to the participants' personal use of toothpaste and tooth brushing.' P2, p437, 438

'Care based on this protocol, when consistently delivered, resulted in measurable improvements in oral cleanliness and patients' perceptions of oral comfort. This is despite the fact that the care provided is neither complicated nor expensive.' P3, p425

However, 'performing oral care' was also a reaction to oral symptoms and oral discomfort, i.e. a reactive approach rather than a proactive approach.

'All participants described an oral care procedure, albeit without much detail. These were mainly a technical act to address oral symptoms and provide comfort. When oral care was not provided this was in order to avoid causing stress to their loved one and was usually because they had been advised not to so. It appears that generally oral care was provided in reaction to signs and symptoms rather than to pro-actively improve quality of life.' P1, p4

There seems to be opposite views regarding timing of oral care. Authors' concluded that HCPs argued that oral care should be provided systematically and following thoughtful organisation, rather than when patients chose. One could argue this is not a person-centred approach to care.

'the health-care assistants considered that oral health care should take place systematically during each general hygiene care, rather than following meals or at a time of patient choice...the nurses considered that oral care should be performed when they think it is necessary...it seems that proper oral health should indeed not be automatic but rather a question of thoughtful organisation' P2, p439

‘Promoting comfort’ was the only sub-theme to which all groups contributed to: palliative care patients, relatives, HCPs and authors. This was followed by ‘oral hygiene’ (palliative care patients, relatives and authors) and finally ‘timing of oral care’ (palliative care patients and authors) (Table6).

Table 6: Contribution of participants and authors to themes and sub-themes

Themes	Sub-themes	Contribution of participants			Authors' comments
		Palliative care patients	Relatives/carers	Healthcare professionals	
Performing oral care	Oral hygiene	X	X		X
	Promoting comfort	X	X	X	X
	Timing of oral care	X			X
Effects on oral health	Oral symptoms	X	X		X
	Wider impact of oral symptoms	X			X
	Improving oral symptomology	X			X
Challenges in palliative care	Wider impact of oral care	X	X	X	X
	Barriers to oral care	X	X	X	X
	Overcoming challenges in oral care				X

Effects on oral health

Palliative care patients, relatives and the authors of three studies (Bernardes Delgado *et al.*, 2018; Milligan *et al.*, 2001; Rohr, Adams & Young, 2010) contributed to this theme. However, HCPs did not. This theme includes 'oral symptoms' such as dry-mouth, ulcers, thrush, experienced by patients and witnessed by their relatives. Xerostomia or dry-mouth was the symptom mentioned more often by palliative care patients and relatives. The other oral symptoms came secondary to xerostomia.

'his mouth is totally dry and obviously very unpleasant' P1, p3

'When the thrush was happening... I got the very unpleasant taste in my mouth... Well I'm not eating very well anyway' P4, p440

Nonetheless, there is a 'wider impact of oral symptoms'. Palliative care patients described being cross, short tempered and irritated about not being able to taste food and having difficulty eating and speaking. They were also conscious of the impact their mouth had on others, namely its potential smell.

'My mouth is very dry, sometimes my mouth gets stuck, I've got a job to speak clearly, I sip water to be able to say anything... seems to have gone on forever... a bit short tempered... with trying to repeat yourself [Interviewer: "so you find it a bit frustrating?"] yeh, because it's there all the time.' P4, p442

'And also, I can be conscious about a smell coming out of my mouth... I clean it, I clean it of course... well I don't know if there's a smell. I can't smell myself.' P4, p442

In addition, if patients couldn't taste what was the point in eating?

'You have no taste... And that's what makes me so cross, because taste to me is a lot... what's the use of bloody having it? Let's face it, if I can't, if I can't taste food I won't eat.' P4, p441, 442

Palliative care patients also described how to improve their symptoms: ‘improving oral symptomatology’. Drinking sips of water and certain mouthwashes seemed to have helped. However, often that was not the case, regardless of what was tried.

‘All those mouthwashes really make a difference.’ P3, p424

‘My mouth is very, very dry, sometimes my mouth gets stuck, I’ve a job to speak clearly, I sip some water to be able to say anything... my voice will come louder...’ P4, p442

‘Nothing helps. I tried honey, and a cup of tea, and chamomile tea. It doesn’t help. I tried all kind of lollies. It doesn’t help...’ P4, p443

This theme with its three sub-themes had the greater contribution from palliative care patients and the authors of three studies. ‘Oral symptoms’ was the only sub-theme to which relatives also contributed. ‘Wider impact of oral symptoms’ and ‘improving oral symptomatology’ had only the contribution of palliative care patients and the authors of three studies (Table6).

Challenges in palliative care

This theme has three sub-themes: ‘wider impact of oral care’, ‘barriers to oral care’ and ‘overcoming challenges in oral care’. However, only two sub-themes had the contribution of palliative care patients, relatives, HCPs and authors of three studies (Bernardes Delgado *et al.*, 2018; Croyere *et al.*, 2012; Rohr, Adams & Young, 2010): “wider impact of oral care” and “barriers to oral care”. Only the authors of two studies (Croyere *et al.*, 2012; Rohr, Adams & Young, 2010) contributed to the sub-theme: ‘overcoming challenges in oral care’.

The 'wider impact of oral care' relates to the effect performing oral care had on relatives and HCPs. Relatives described revulsion and worry at having done something that caused their loved one's harm.

'As I removed the sponge every other person in the room reacted with revulsion' P1, p4

'we were anxious to keep him as comfortable as possible so continued to offer the swab dipped in water. The problem is that I can't stop worrying about the fact that we might have caused him to choke.' P1, p4

HCPs felt performing oral care violated theirs and the patients' personal space and there was also little reward in providing oral care.

'participants, who reported that it violates the personal space of both parties and generates feelings of disgust about bad breath. The nursing staff also felt that these unpleasant feelings were reciprocated by the patients. The participants reported that they would not like to receive oral care but they would also not like not to receive it. They felt there is little reward in carrying out mouth care as it needs to be repeated frequently.' P2, p438, 439

Palliative care patients reported their loss of independence and what they perceived as being humiliating to them.

'It's [staff assistance with oral care] humiliating... I'm so, I like to be independent... I'm a very independent person...' P4, p442

The 'barriers to oral care' included not knowing how to perform oral care, the confusion regarding guidelines and products and the refusal to accept oral care from some patients. It was also not a priority and the oral cavity was seldom being assessed.

'There was confusion over the choice of products and resources. This confusion was related to different recommendations given by the mobile palliative care teams, to the variety of medical prescriptions, and to changes in the guidelines, which led

to participants not knowing whether they were current or pertinent. Other points of confusion were due to organisational and logistical factors, such as availability of resources and products constantly changing, for various reasons. The cost of different products could be an issue, as could changing recommendations and the need to test new resources like soft toothbrushes. The participants reported that they ultimately provide the oral care they think is appropriate with the resources they are comfortable with. ' P2, p438

'in the focus groups, participants who indicated that patients sometimes refuse oral health care explained that these refusals were often due to patients finding the care painful and/or unpleasant because of neurological problems, or that they were a means of expressing distress' P2, p438

'No-one has looked in my mouth. The outreach nurses come, they say the same thing – just wash it out.' P4, p443

'Ah, no-one's actually come over and gone 'ahhh', you know. They've been sitting on that side of the table I've been sitting on this side of the table.' P4, p443

'Overcoming challenges in oral care' is a sub-theme identified from the authors'

comments and their conclusions from two studies (Croyere *et al.*, 2012; Rohr, Adams & Young, 2010). These were practical suggestions on how to overcome some barriers HCPs had in providing oral care. Examples included role playing of patients refusing oral care and identifying the appropriate resources and using them correctly. Authors also stated the importance of positive feedback and to witness a positive outcome from providing oral care.

'The analysis of the focus group responses found that there are issues that need to be addressed in order to reinforce caregivers' feelings of effectiveness in carrying out oral care for patients in palliative care. Addressing these practical points can take different forms, such as exercises within and outside the clinical setting (e.g. role play of a patient refusing oral care), identifying appropriate resources and their correct use, etc. During handover, discussions can take place about the appropriate moment for oral care for both the caregiver and the patient. A caregiver who feels at ease carrying out oral care can accompany another who feels uncomfortable. Also explicit positive feedback can be elicited from patients, families clinical specialists, managers, and other stakeholders.' P2, p439

'Focus groups involving oral caregivers showed that it is necessary for caregivers to feel that they and their colleagues are successful in carrying out oral care and to witness a positive outcome in order to feel convinced that good oral care is necessary.' P2, p440

Furthermore, oral care to palliative care patients should be given higher priority so professionals' standards could be improved.

'The results of this study are supportive of oral care for the terminally ill patient being raised to a clinical priority in hospice, acute hospital, and palliative community outreach settings to improve standards of professional holistic palliative care.' P4, p444

3.5 Discussion

This qualitative systematic review identified four articles related to the oral care experiences of palliative care patients, relatives and HCPs. The main findings of the qualitative data synthesis were three themes: 'performing oral care', 'effects on oral health' and 'challenges in palliative care'.

Palliative care patients were the greater contributors to the themes and sub-themes generated by the thematic analysis. This is not surprising when one considers that they were the participants of two of the four studies included (Milligan *et al.*, 2001; Rohr, Adams & Young, 2010). One could also argue that their 'voices' were heard through their relatives in another study (Bernardes Delgado *et al.*, 2018).

'Effects on oral health' was about what happens to them, including the 'oral symptoms', but also the 'wider impact of oral symptoms' and how to address 'oral symptomatology'. Palliative care patients contributed more to this theme than to the other two. 'Oral symptoms' in particular were important for these studies' participants. It is known that oral health problems experienced by palliative care patients have a great impact on their quality-of-life (Aldred *et al.*, 1991; Fitzgerald & Gallagher, 2018). In addition, as systemic health deteriorates so does oral health (Chen *et al.*, 2013b).

However, oral symptoms have a wider impact beyond the discomfort and pain caused. Patients' social interactions with others were compromised. There was difficulty talking and swallowing, but also how one presented himself/herself to others became complicated and was often embarrassing. The literature on palliative oral care focus on describing oral symptoms and how to manage these (Quinn, 2013; Sargeant & Chamley, 2013; Wiseman, 2000; Wiseman, 2006). There is a lack of understanding and research on the wider impact of oral symptoms to palliative care patients and how they affect their quality-of-life (Fitzgerald & Gallagher, 2018). This study has provided an insight into the range of psychological consequences of oral symptoms.

There were conflicting statements on what worked and what did not work on addressing oral symptoms. For some participants, simple measures such as mouthwashes would be enough. Nevertheless, for other patients nothing seemed to work. These seemingly conflicting statements are also reflected in the literature. On one hand, it is recognised that simple oral care measures, such as tooth brushing, denture hygiene, moisturising, use of anti-fungals, are effective in improving oral health for palliative care patients (Kristanti, Setiyarini & Effendy, 2017; Nakajima, 2017). On the other hand, there is confusion on which guidance to follow and which products to use (Kvalheim *et al.*, 2016). Oral care to these individuals is considered inadequate and dental professionals are seldom involved (Kvalheim *et al.*, 2016; NHS Scotland, 2014; Saini *et al.*, 2009).

Palliative care patients contributed to the other two themes 'performing oral care' and 'challenges in palliative care'. Their 'voices' were more subdued in these themes. They would clean their mouths and their teeth and would use certain products to mitigate some of the discomfort. However, their oral care routine changed as their health deteriorated and as they had to leave home. In addition, becoming more dependent on others for oral care was perceived as humiliating. Moreover, HCPs did not seem to care

or assess patients' mouths. This was the patients' perception and there was a distance between healthcare professionals and patients. The opposite of a person-centred approach to oral care was defended by HCPs. Oral care should be delivered in a systematic way and not when patients chose. Palliative oral care is often delivered in an unstructured and haphazard way and it is not evidence-based (Kvalheim *et al.*, 2016). In addition, HCPs' priorities and what the individuals receiving oral care value is rarely taken into account (NICE, 2016).

Relatives also contributed to all three themes but to less sub-themes than patients. They described without much detail some oral hygiene measures. These were performed ultimately to provide comfort and alleviate symptoms. Indeed, relatives were the greatest contributors to the sub-theme 'promoting comfort'. It seems that 'oral hygiene' was secondary to 'promoting comfort' to relatives.

Relatives also described oral symptoms they could observe for themselves. Although, this was often when oral health was already severely compromised. In terms of the 'challenges in palliative care' relatives described difficulties in providing oral care for someone else. This is also the experience described by HCPs in providing oral care in other studies (Couch, Mead & Walsh, 2013; Kvalheim *et al.*, 2016).

HCPs only contributed to two themes and they did not contribute to 'effects on oral health'. They were concerned with the notion of promoting comfort through oral care measures. However, the emphasis was on the challenges of providing oral care. It is a very personal care and some staff considered that it violates theirs and patients' personal space. In addition, there was the perception that there is little reward in carrying oral care as it had to be repeated frequently. It was also recognised by the authors that caregivers did not acknowledge the psychological impact of the oral care provided. This

care was not perceived as being rewarding by HCPs because they did not recognise its value on the individual's positive self-image. There were also important barriers to the provision of oral care. HCPs were confused about what to do and what products to use. The literature reflects this aspect as most oral care procedures are not evidence-based and there are also staff and time pressures (Kvalheim *et al.*, 2016). Furthermore, patients' cooperation with oral care can be challenging and some patients refused this care. HCPs stated it was painful and uncomfortable to patients. Some patients also had neurological problems which were another 'barrier to oral care'. Palliative care patients stated that there was a distance between them and HCPs. Nobody looked in the mouth and they would be given the same advice regarding of the complaint. Once more, this emphasises a lack of a person-centred approach to oral care and a one measure fits all approach, which is not the ethos of palliative care.

Authors also added to the points mentioned above that patients were tired and fatigued which created difficulties with the oral care routine. Patients felt HCPs could not help. Therefore, there was no point in conducting an oral assessment. There was this sense of hopelessness from palliative care patients. Nevertheless, authors offered recommendations on how to overcome the above challenges.

The authors of the included articles also made a direct connection between oral hygiene and comfort and presented an explanation as to why cleanliness was so important to HCPs. They made the assumption that it was to do with the HCPs' own oral care routine. In addition, authors' concluded HCPs defended oral care should take place systematically and not only after meals or at a time of patients' choice. Once again, this is the opposite of a person-centred approach to oral care.

3.6 Limitations

The limitations to this qualitative systematic review should be acknowledged. Two of the four studies included were of poor methodological quality. However, the researcher prioritised the relevance of the studies over their methodological quality. This approach is defended by Dixon-Woods *et al.* (2006). Data of the four included studies contributed to the thematic analysis identifying the themes and sub-themes. Therefore, the interpretation and transferability of findings requires caution. Nonetheless, studies with higher methodological quality contributed more to the findings.

This systematic review included only qualitative studies. Consequently, quantitative studies might have contributed to a wider understanding of oral care experiences in palliative care. A mixed-method systematic review is therefore suggested as the findings of this review might be limiting a wider understanding of the phenomena.

One of the early challenges with this research was how to define the population of interest. Even though the researcher made a conscious decision to use the terminology 'palliative care patients' instead of 'terminally-ill patients' or 'end-of-life patients', this is a broader concept and difficult to define. 'Palliative care' includes 'terminally-ill patients' and those receiving 'end-of-life care'. Therefore, studies that had as their participants 'terminally-ill patients' and those receiving 'end-of-life care' were included. However, and as presented in the introduction to this thesis the definition of palliative care is not unanimous. It was decided to include adult patients receiving palliative care as per the WHO (2004a) definition. Consequently, it had to be clear within the studies that this was the case. Thus, if there was any ambiguity within the papers, these were excluded.

Another limitation encountered in this review was the fact that it was not possible to describe the background of the findings fully. The studies included provided limited information regarding context into which the studies took place and participants involved. Indeed, with some studies it was not possible to ascertain the patients' diagnosis. This poses obstacles to the transferability of findings. Since limited information was given within this study, those that wish to transfer the findings to other sites are not likely to be able to judge the transferability of the results (Nowell *et al.*, 2017).

In addition, participants could not be probed as only secondary data were analysed. It was not possible to conduct member checking as defend by Braun and Clarke (2013). Nevertheless, rigour was insured through the consultation with a second experienced reviewer.

3.7 Conclusion

Research on palliative oral care is scarce (Fitzgerald & Gallagher, 2018; Kvalheim *et al.*, 2016) and this qualitative systematic review confirms this as only four articles were included.

The three themes identified from the four studies tell a story of what is important to palliative care patients, relatives, HCPs and authors regarding oral care. With some sub-themes such as 'oral hygiene' and 'promoting comfort' all groups seemed to share a similar view. None of the participants or authors provided much detail about what was being done to achieve cleanliness and comfort. However, comfort was the priority and seemed to be the ultimate goal of performing oral care.

Patients described the multitude of oral symptoms they were experiencing, described the wider impact oral symptomatology had on their quality of life and also how to alleviate symptoms. It is interesting to notice that HCPs did not contribute at all to this theme and relatives contributed very little. Relatives were aware of oral symptoms, but they did not seem to acknowledge their wider impact. It appears that HCPs and relatives were not aware of the enormous psychological ramifications of not being able to speak, taste and swallow.

All groups experienced different challenges with oral care. Palliative care patients experienced the loss of independence and unmet needs from HCPs. Relatives experienced feelings of revulsion and worry about the oral care of their loved ones and HCPs were confused regarding oral care provided and where to look for guidance. In addition, it appears that HCPs experienced little reward in performing oral care. One can question whether oral care would still be considered such an unrewarding task, were HCPs more aware of the enormity of the consequences of poor oral health for patients?

The findings of this review contributed to start answering the research question: *‘what are the oral care experiences of palliative care patients, their relatives/carers and HCPs?’* This review provided evidence of what these experiences may be. Despite similarities between the groups in terms of the oral symptoms experienced and observed and the goal of oral care procedures, this review also identified some differences. The main priorities for relatives and HCPs of delivering oral care seemed to have been cleanliness and comfort. In addition, these groups seemed to have ignored the wider impact of oral symptoms. Moreover, the challenges experienced differed between groups. Therefore, this confirmed the need to investigate further the wider impact of oral symptoms and the challenges of palliative oral care to the different stakeholders.

CHAPTER 4: The oral care experiences of palliative care patients in a hospice in the South-West of England. A qualitative study.

The next stage of this research project was to ask palliative care patients, relatives/carers and HCPs the research questions directly. An interview study was designed to explore the gaps in knowledge identified with both the study of blogs and discussion forums and the qualitative systematic review described in chapters 2 and 3 respectively.

Chapter 4 describes the interview study that took place in a hospice in the South-West of England. Similarly, to chapter 3, and in order to maintain consistency of presentation throughout the thesis, this chapter is presented as a ready to submit manuscript. The researcher sets out the aims and objectives of the primary research study, the methodology used and its justifications, explains the ethical considerations and presents the findings of the study. The oral care experiences of palliative care patients, relatives/carers and HCPs continued to be examined.

4.1 Introduction

The oral health of palliative care patients is a topic rarely explored from the dental perspective (Fitzgerald & Gallagher, 2018). It is usually examined from a nursing perspective (Fitzgerald & Gallagher, 2018) and the experiences of patients are rarely described (Bernardes Delgado *et al.*, 2018).

This fact seems surprising when one considers that oral symptoms are amongst the most common symptoms palliative care patients experience (Kinley & Brennan, 2004; Kvalheim *et al.*, 2016; Milligan *et al.*, 2001; NICE, 2018). This happens in spite of some authors arguing that oral problems are underreported by patients (Wilberg *et al.*, 2012). It seems that oral symptoms caused by head and neck cancer and its treatment are numerous and well documented. However, with cancers in other areas of the body, oral symptoms are less well-documented and systematic oral care protocols are seldom encountered (Wilberg *et al.*, 2012).

Furthermore, oral complications are inadequately addressed by clinicians and dental professionals are not routinely involved in the care of these individuals (Saini *et al.*, 2009; Wilberg *et al.*, 2012). The oral care of palliative care patients is often neglected and inadequate (Kvalheim *et al.*, 2016; NHS Scotland, 2014). Some of the explanations given are the lack of resources, lack of time and inadequate staff training (Kvalheim *et al.*, 2016). Moreover, research on this field is scarce and oral care procedures are often not evidence-based (Bernardes Delgado *et al.*, 2018; Fitzgerald & Gallagher, 2018; Kvalheim *et al.*, 2016). Finally, the individuals with the greatest stake on the subject, palliative care patients, appear not to have been given a voice.

4.2 Research problem

The research problem stated throughout this thesis remains the same. Although, a greater understanding of the oral care experiences of palliative care patients, their relatives and HCPs has been reached with the previous two studies, there are still gaps in knowledge. The research questions have not been answered fully.

Consequently, the research questions remain:

- What are the oral care experiences of patients during palliative care?
- What are the experiences of those who provide oral care or support palliative care patients in their oral care, such as relatives, carers and HCPs?

One-to-one interviews were conducted to explore the ‘lived’ subjective experiences of palliative care patients, relatives and HCPs, regarding oral care.

Aim and objectives

The aim of this qualitative study was to explore the lived experiences of palliative care patients, their relatives and HCPs regarding the provision of oral care. More specifically the objectives were:

- To explore the oral care experiences of palliative care patients in a hospice in the South-West of England;
- To explore the oral care experiences of those delivering oral care to palliative care patients in the same hospice. The patients’ relatives and HCPs’ experiences.

4.3 Methods

Theoretical approach

Similarly, to the stance taken with the previous qualitative review study, the researcher's ontological and epistemological positions were critical realism. Critical realism integrates a realist ontological position with a constructivist epistemological position. (Maxwell & Mittapalli, 2010). Knowledge of reality is shaped by people's beliefs, perceptions, experiences, history and culture (Barnett-Page & Thomas, 2009; Edmunds & Brown, 2012).

The aim of this primary research study was to explore the oral care experiences of palliative care patients, relatives and HCPs. The researcher adopted a realist ontological position in which it is believed reality exists independently of people's perceptions and constructions. Nevertheless, the researcher also argued that the way people understand reality is a construction of their own perspectives, i.e. constructivist epistemology.

In order to study the 'lived' experiences of participants a phenomenological approach was adopted. However, phenomenology is more than an approach. It is simultaneously a philosophy, a method and an approach (Lin, 2013). It was conceived in the beginning of the 20th century by Husserl in order to research consciousness as experienced by the subject (Baker, Wuest & Noerager Stern, 1992).

Phenomenology is a theoretical position used in qualitative research when the aim is to provide insight into the 'lived' experiences of individuals (Edmunds & Brown, 2012). It is presented as an approach ideally placed when the focus of the research are human experiences and their meaning (Lin, 2013). It introduces the concept of perspective, in that there is a phenomenon when there is a subject who experiences it (Araujo Sadala & Camargo Ferreira Adorno, 2002).

Husserl developed four notions that are considered central when phenomenology is applied: intentionality, description, reduction and essence (Baker, Wuest & Noerager Stern, 1992). Consciousness is intentional as it is always consciousness of something, and through it, all human actions and behaviour have a meaning (Araujo Sadala & Camargo Ferreira Adorno, 2002). In addition, the description of a phenomenon as experienced by the subject or individual is the object of study (Baker, Wuest & Noerager Stern, 1992). In order to ensure the reliability of the phenomenon's description, reduction or bracketing is fundamental (Araujo Sadala & Camargo Ferreira Adorno, 2002; LeVasseur, 2003). Reduction or bracketing entails putting aside preconceptions about the phenomenon being researched and therefore allowing the identification of its essence (Baker, Wuest & Noerager Stern, 1992).

Phenomenological bracketing is not without controversies and its relevance depends on the type of phenomenology considered. This debate is outside the scope of the thesis as despite phenomenology being the approach adopted, the method of data analysis chosen was thematic analysis. Thematic analysis is not bounded to any pre-existing theoretical framework, and as a consequence can be used within different theoretical frameworks such as phenomenology (Braun & Clarke, 2006). Thematic analysis has a long history as a phenomenological method and it predates interpretative phenomenological analysis (IPA). Nevertheless, it is important to acknowledge that if on one hand descriptive phenomenology is committed to bracketing, hermeneutic (interpretive) phenomenology is not (LeVasseur, 2003).

In this study the researcher adopted a hermeneutic phenomenological approach and employed bracketing as defended by LeVasseur (2003) and by Elliott et al., (1999). The principal investigator attempted to go beyond ordinary assumptions of the phenomenon and stayed curious about it. There was a temporary suspension of prior knowledge to

allow new perceptions, not a permanent suspension. Indeed it is not possible to set aside the researcher's own perspective entirely (Elliott, Fischer & Rennie, 1999). Reflexivity, is a way of bracketing existing theories and the researcher's own values in order to understand and represent the participants' experiences (Elliott, Fischer & Rennie, 1999).

The purpose of a phenomenological philosophy is the discovery of the essence of the participants' experiences, of the phenomenon being studied (Baker, Wuest & Noerager Stern, 1992). The essence of a phenomenon can be described as its essential meaning, it is what makes the phenomenon what it is (Dahlerg, 2006). With hermeneutic phenomenology the focus is on understanding the meaning of experience. In order to do so, the researcher searches for themes and engages with the data interpretively (Araujo Sadala & Camargo Ferreira Adorno, 2002).

Researcher's own perspective

The researcher is a female in her mid-30s, Caucasian, born in Portugal and with a traditional middle-class upbringing. The researcher has been living and working as a dentist in England since 2009. Currently works in a community dental service in the South-West of England. The researcher provides NHS dental care for individuals with additional needs and children from deprived backgrounds who present high dental treatment needs. Individuals with additional needs include, but are not limited to, patients who have learning difficulties, are medically-compromised, have dental phobias and those who are older and frail. Regular clinical work includes treating patients who are too unwell and frail to leave their homes. Through this work, the researcher has become acutely aware of the impact systemic health can have on one's oral health and vice-versa. In addition, the researcher recognises the importance of a patient-centred approach and values a holistic and multi-disciplinary approach to care.

However, the researcher has not treated many patients receiving palliative care. Her personal experience with a family member receiving palliative care and her professional background provided the researcher the motivation to consider oral care in palliative care patients. These aspects and the limited research on the topic were the main catalysts for this project.

The researcher's personal reflections of the potential impact of her values, assumptions and perspectives may have on the reporting of findings from participants and her interpretation of these findings are explored on the conclusion chapter of this thesis.

Ethical considerations

The primary research study was designed to include as participants: palliative care patients, their relatives and HCPs. This raised several ethical considerations not only regarding the participants themselves, but also regarding the researcher. These are some of the considerations taken into account during all the stages of the project:

- Obtaining informed consent;
- Maintaining confidentiality and anonymity of all participants;
- Potential for participants to become distressed during interviews;
- Potential for the researcher to become distressed;
- The researcher's safety during face-to-face interviews.

The study required ethical approval, which was obtained from the University of Plymouth Research Ethics Committee on 17th April 2018 (17/18-908). The approval letter from the Chair of the Research Ethics Committee is presented as Appendix 7.

Design of study

This is a qualitative interview study designed to understand the oral care experiences of participants.

The ‘lived’ experiences of individuals are largely unmeasurable and challenging to describe and understand through sensory observation and traditional research methods. Consequently, traditional science has not focused on topics such as patients’ lived experiences of health and illness. However, for clinicians it is crucial to comprehend the meaning of patients’ experiences in order to promote coping strategies, (LeVasseur, 2003) and to improve acceptability of and compliance with treatment.

Qualitative research is concerned with the human experience and the analyses of words and their meanings (Edmunds & Brown, 2012; Elliott, Fischer & Rennie, 1999). It recognises that data is collected within a context and seeks to explore, understand and interpret meaning (Braun & Clarke, 2013; Stewart *et al.*, 2008). The relationship between the subject and environment is fluid and reciprocal; both influence each other (Braun & Clarke, 2013).

Rather than seeking to make claims based on the statistical generalisability of the results, the aim of this primary research study was to generate rich, in-depth, multifaceted accounts concerning the oral care experiences of palliative care patients at a hospice in the South-West of England, the oral care experiences of their relatives and HCPs working at the same hospice. Ultimately, and in line with the phenomenological approach adopted, the aim was to discover the essence of the oral care experiences of the participants of the study and the meaning of these experiences.

As stated in the introduction to this chapter there is little research available on the phenomenon of interest. This suggests it is a challenging area to study and data is

difficult to access. In order to overcome some of the challenges to the research, the principal investigator engaged in Patient and Public Involvement (PPI) work to inform the study design. This comprised of an informal consultation with staff at the hospice; the director of patient care and the inpatient unit manager. Subsequently the researcher attended meetings held by the user group of the hospice; a meeting attended by relatives of patients and former patients at the hospice. During these meetings the researcher presented the study and received feedback regarding the design of the project. This provided insight into the feasibility of the sampling process and recruitment of participants. The user group also provided feedback on the proposed interview questions.

The researcher became familiarised with the research governance process at the hospice and the relevance of the research topic to the target population. Approval was sought from the Quality and Patient Safety Committee at the hospice. The letter of support from the chair of the committee, with two suggested amendments, is included as Appendix 8. These amendments were incorporated in the ethical application. It is argued that PPI ensures the appropriateness and relevance of research and consequently enhances its quality (Brett *et al.*, 2012). PPI carried out in the initial phase of a research project also helps identifying user-relevant topics (Brett *et al.*, 2012).

Method of sampling and recruitment of participants

Studies that adopt a phenomenological approach are designed to access and describe the essence of the phenomenon of interest. As a consequence, participants are chosen due to their 'lived' experience of the phenomenon. Sampling is purposive in order to achieve this very aim. Additionally the sample size is kept small so the richness of the individual experience can be accessed (Baker, Wuest & Noerager Stern, 1992).

Therefore, the sampling method used in this primary study was purposive sampling, to include patients, relatives, and HCPs with a range of genders, ages and health conditions when applicable. This would prevent certain groups of participants to be overrepresented and the researcher would be able to access data from different perspectives. As defended by Braun and Clarke (2013) the aim of purposive sampling is to generate in-depth understanding rather than generalise findings as happens with quantitative research. However, the approach to sampling was necessarily pragmatic due to the ability and availability of individuals to be interviewed at the hospice. In addition, most palliative care patients were being treated in the community and only a small number were inpatients at the hospice. Patients would stay in the hospice for usually no more than two weeks. There was an average of 20 inpatients, and these tended to be patients with poorly controlled symptoms that were very unwell or receiving end-of-life care. This created difficulties in attempting to include patients with diverse health conditions as demonstrated in the demographic table presented below.

Twelve participants were recruited and interviewed: four palliative care patients, four relatives and four frontline healthcare professionals at the hospice. Six to ten interviews is considered to be sufficient to generate enough in-depth data for a small research project (Braun & Clarke, 2013). Moreover, in order to describe the essence of the phenomenon and the richness of the individual experiences, the number of participants is intentionally kept small (Baker, Wuest & Noerager Stern, 1992).

Participants were not excluded based on gender, age, health condition, number of years working at the hospice. The researcher wanted diversity of perspectives and the sample to include a range of health conditions as the study aimed to gather data from non-cancer patients as well. However, all palliative care patients interviewed had a cancer diagnosis (Table 7). This is a limitation of the study and will be discussed in more detail

at the end of this chapter. Diversity and richness of individual experiences was achieved by interviewing three different groups. Participants included eight females and four males, their age ranged from 42 years old to 90 years old. In addition, the year of diagnosis was different and so was the number of years as carers or working with palliative care patients. Each one of the three groups also presented some heterogeneity within itself, as shown in Table7.

Individuals were recruited with the assistance of staff members at the hospice. Participant information sheets were left in patient, relatives and staff areas and can be found in Appendix9. These forms included information about the study, the researcher's contact details, link to the study webpage and a section that potential participants filled out and left with the receptionist at the hospice if they wished to take part. The receptionist would then contact the principal investigator who attended the hospice and met potential participants. During this informal meeting the principal investigator would describe the study, answer any questions and if both parties wanted to proceed to an interview then the consent process would take place and finally a consent form would be signed by both parties (Appendix10). An interview would then be arranged, and a private space would be booked. If patients were unable to move from bed some privacy would be created with curtains for example. However, this constituted a compromise and will be discussed in the limitations' section.

Data collection

The method used to collect data was individual, face-to-face, semi-structured interviews. These were audio-recorded and transcribed verbatim by the researcher. Interviews are the most common method of data collection in qualitative research and the semi-structured format the dominant form (Braun & Clarke, 2013). Braun and

Clarke (2013) argue that interviews are the ideal method for experience type research questions. When individuals have a personal stake in a topic, as the current participants did, interviews are likely to generate rich and detailed data.

A phenomenological approach entails that data is collected free from preconceived ideas (Baker, Wuest & Noerager Stern, 1992). Consequently, interview questions should be open-ended and designed to avoid influencing participants (Baker, Wuest & Noerager Stern, 1992). A semi-structured format was utilised as a guide (Appendix 11), however it was not rigidly adhered to. This gave participants the opportunity to discuss topics that mattered to them which may not have been anticipated by the researcher and may not have been in the interview guide (Braun & Clarke, 2013). It provided a more flexible methodology which was considered to be aligned with the aims and objectives of this study.

Considering the potential vulnerability of participants, one-to-one interviews were considered a more sensitive approach than focus groups. In addition, palliative care patients were likely to be feeling unwell, therefore interviews provided a flexible approach as could be conducted in a more private space and time of choice. Finally, interviews can generate adequate data with smaller samples (Braun & Clarke, 2013). Consequently, the researcher could generate rich data by interviewing fewer participants.

As suggested by Braun and Clarke (2013) the researcher also took field notes on aspects that could provide additional insight into the data. These included notes on what was happening, such as who the participant was, where the interview was taking place, and on the researcher's thoughts and feelings about what was happening, such as how relevant the questions seemed to be to the participant. This process enabled the

researcher to reflect on how the interviews were being conducted. As a result, some adaptations, such as limiting the interviews to two a day, were made. The field notes were also used as a tool to develop a richer and more complex analysis. An extract from the researcher's diary is presented below:

P2 12/09/2018

What is happening: *'I interview an old, male patient who is lying on his bed during the interview. He is frail and finds it difficult to talk.'*

My thoughts about it: *'I feel I should not be here asking these questions, when he is obviously so poorly. These questions are not really that important, he obviously does not care anymore.'*

Table 7: Demographic data

Participants	Age at the time of interview	Gender	Ethnicity	Diagnosis (patients only)	Year of diagnosis (patients only)	Number of years as a carer (relatives only)	Number of years working with palliative care patients (healthcare professionals only)
P1	50	Female	White British	Cancer	2015	n/a	n/a
P2	74	Male	British	Cancer	2 months before interview (2018)	n/a	n/a
P3	90	Male	British	Cancer	2016	n/a	n/a
P4	70	Male	White British	Cancer	June 2018	n/a	n/a
R1	42	Female	British	n/a	n/a	4 months	n/a
R2	75	Female	British	n/a	n/a	20 years	n/a
R3	62	Male	British	n/a	n/a	n/a	n/a
R4	57	Female	British	n/a	n/a	6 months	n/a

H1	42	Female	White British	n/a	n/a	n/a	10 years
H2	50	Female	British	n/a	n/a	n/a	2 ^{1/2} years
H3	58	Female	White British	n/a	n/a	n/a	31 years
H4	51	Female	British	n/a	n/a	n/a	27 years

P: palliative care patient;
R: relative;
H: healthcare professional.

Method of data analysis

A phenomenological approach was adopted for this project as the researcher wanted to study the ‘lived’ experiences of participants regarding oral care, discover the essence of the phenomenon (oral care experiences) and understand the meaning of these experiences. IPA was considered as a possible methodology. However, the method employed to analyse the data was thematic analysis. This choice was justified in previous sections to this chapter. Thematic analysis can be used as phenomenological method of data analysis particularly when to focus on a patterned meanings across the data-set and not so much on the distinctive characteristics of individual participants (Braun & Clarke, 2013).

Thematic analysis is a particularly useful method to describe and examine perspectives of different participants, to highlight their differences and similarities and subsequently to lead to greater insight into the data (Nowell *et al.*, 2017). Nevertheless, its flexibility can lead to inconsistency when developing themes and analysing data (Braun & Clarke, 2013; Nowell *et al.*, 2017). Therefore, the researcher considered quality criteria such as trustworthiness, validity, transferability and will discuss these in the latter sections. In addition, and as defended by Elliott *et al.*, (1999) the researcher disclosed the theoretical stance adopted, professional background, training and assumptions relevant to the subject matter, i.e. owning one’s perspective.

Furthermore, the researcher followed the six stages described by Braun and Clarke (2006) to analyse the data. These stages were described in the previous two chapters as the same method was applied to analyse data of the study of blogs and discussion forums and the qualitative systematic review. Nonetheless, a brief explanation of how the interviews were analysed is described below:

1. Familiarisation with the data: the researcher transcribed verbatim the 12 interviews and uploaded the transcription files into NVivo 12, a qualitative data analysis software programme (Bazeley & Jackson, 2013). This process enabled the researcher to become familiarised with the data corpus and helped with data analysis. The researcher immersed in the data, read and re-read the data corpus in its entirety.
2. Generation of initial codes: the researcher 'listened' to what the data was telling her rather than applying prior categories from the literature or from the researcher's own experience. This was an inductive process in that initial codes, such as 'difficulty in getting to the dentist' and 'a home visit from the dentist would be helpful', were identified in a data driven way.
3. Search for themes: the analysis was re-focused at the broader level of themes. The researcher sorted the long list of initial codes into potential themes. For example, the two initial codes stated above were incorporated into a broader theme: 'access to dental professionals'.
4. Review of themes: potential themes were refined during this stage. Following the example above, 'access to dental professionals' became a sub-theme in the broader theme 'enablers and barriers to oral care'.
5. Define and name themes: during this phase the researcher identified the essence of what each theme was about.
6. Produce a report.

A second researcher (SG) was involved in the analysis and reviewed, questioned what was done, how it was done and the rationale for the decisions made. This process ensured the rigour of analysis.

4.4 Findings

The thematic analysis of the interviews identified three themes regarding the oral care experiences of the participants: ‘performing oral care’, ‘effects on oral health’ and ‘enablers and barriers to oral care’. In addition, within each theme further sub-themes were identified (Table 8):

- ‘Performing oral care’: ‘oral care by self’ and ‘oral care by others’;
- ‘Effects on oral health’: ‘oral symptoms’, ‘exacerbating factors’ and ‘everyday relieving factors’;
- ‘Enablers and barriers to oral care’: ‘attitudes’; ‘training, guidelines and advice’, ‘learning from experiences’, ‘access to dental professionals’ and ‘fatigue’.

Table 8 presents some illustrative quotations from participants of the themes and sub-themes, generated by the researcher. In addition, Table 9 shows which group of participants contributed to the themes and sub-themes. In this study palliative care patients, relatives and HCPs contributed to all themes and most sub-themes.

Table 8: Quotations from participants of themes and sub-themes

THEMES	SUB-THEMES	Palliative care patients	Relatives	Healthcare professionals
Performing oral care	Oral care by self	<p><i>'I normally brush my teeth in the morning'</i> P1</p> <p><i>'basically small amounts of toothpaste a couple of times a day and I used to have chewing gum cause when you have sugar chewing gum is meant to help you but I can't stand the taste of chewing gum anymore...'</i> P1</p> <p><i>'Nooo. I was on me own. Sometimes I did me teeth, sometimes I didn't do me teeth.'</i> P2</p> <p><i>'No not difficult (coughs). The nurses remind me to do me teeth (both laugh)'</i> P2</p> <p><i>'You brush? Yeah twice a day Twice a day. Do you use anything else? No'</i> P3</p> <p><i>'I do have a spray that's called (inaudible) I do have a spray but I also have diabetes so lemon spray. So I use that yes.'</i> P4</p>	<p><i>'He has never been that fussy. He cleans them. He cleans them in the morning but he didn't always do it at night. I said you should (laughs). Very fussy!'</i> R2</p> <p><i>'Well she would have looked after her own teeth at home.'</i> R3</p> <p><i>'toothpaste and cleaning yeah, gargle sometimes with listerine but not often. She wasn't that keen on the taste of that.'</i> R4</p>	<p><i>'To encourage them. Yes if they are able to. Well you wouldn't expect them to get in there with the mouthwash and the swabs but you have some lovely toothbrushes some soft brushes hmm don't think you have them in there or maybe we don't have any at the moment. That on the reverse side it's a very soft rubber. Oh yes. And it's got grooves so we encourage them while they brush their teeth after gently to just stroke their tongue and over a period of normally 4 or 5 days you can see an improvement particularly if the top is coated and some of the medication leaves the tongue black.'</i> H2</p>

	Oral care by others	<p><i>'Hmm and when you were at home. Were you looking after your teeth at home? Yes doctor [REDACTED] at Bovey Tracey was my dentist.'</i> P3</p>	<p><i>'Ok hmm so when your mum was at home who was looking after her teeth? The dentist.'</i> R1</p> <p><i>'But luckily she has had a dentist that has seen her regularly and maybe kept her on track.'</i> R1</p> <p><i>'Yeah... 10 days, about a week and then she was back in hospital. I think they were cleaning her teeth with toothbrush and toothpaste.'</i> R3</p> <p><i>'Yeah, yes, yeah I think the dry mouth is a bit better, but whether that's because they've been doing the oralieve in the morning...'</i> R4</p> <p><i>'Here at [REDACTED] I don't know whether it is a specific nurse, I know the nurse, I don't know hmm name actually. She's done it a couple of times, so whether they have set people doing it but I think as soon as they see dentures they'll do them and I know they do care, they do the washing and caring in the morning'</i> R4</p> <p><i>'at home I used to do her dentures for her... Hmm well at first I thought I never done this before, I did ask mum because she was still with it so she told me and did it exactly as she told me. Of course getting the right amount of poligrip (laughs) so funny.'</i> R4</p>	<p><i>'and the other thing that we do use is as well if patients have thrush at the top of their roof of their mouths from wearing dentures we tend to clean their dentures put a bit of (inaudible) in the actual denture. Leave the denture to soak overnight in that. That will help the thrush at the top of their mouth as well. You also tend to take the denture out at night.'</i> H1</p> <p><i>'but you know sometimes patients don't want it in their mouths and obviously we use an "oralieve" toothpaste if patients have got swallowing difficulties so we use "oralieve" toothpaste... it doesn't create much foam so obviously it can be swallowed and there is no harm affected by it either.'</i> H1</p> <p><i>'then normally finish with a little bit of oralieve gel on the tongue, which we do use here which is a lovely product. And then Vaseline on the lips and then obviously we would document it. Is that to keep everything moist? Yeah yeah if a tongue is very coated then either we use those twizzle sticks that you've got there or the back of the toothbrush whilst they are brushing their teeth. And then gently help them with that hmm and hmm hmm probably if they are able to, encourage them to use the mouthwash to rinse and spit it out. But it's not that many that can use the mouthwash and able to spit it out so I tend to use it on the swabs.'</i> H2</p>
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				<p><i>'Hmm then it is not really an issue because it is accepted that it is happening often. You will hear if there's a problem not it it's all happy you know? Hmm whereas if a patient was in bed semi-conscious or unconscious lying there the family would know if they're here they would be made aware of all the care that we are giving. We would be repositioning, the drugs that we are giving and why and also mouth care is a big component of that and is also very obvious because they see us doing it frequently.'</i> H3</p> <p><i>'The thing is that sometimes you have people that are quite well and then you have people that are unconscious that we would do different mouth care for different patients and hmm generally if a patient was awake and mobile you know, up and about, we would do exactly the same mouth care as they've always done at home.'</i> H4</p> <p><i>'When a patient comes in we do an admission and that's one of the things the trained nurses, part of their admission is to look into someone's mouth, check for thrush, if it's sore and go through what they would normally do hmm what care would we need to do for their mouths, whether they would need an anti-fungal if they got thrush or whether we need to brush their tongue if it's coated. So we would have a plan of what we would need to do and then we would document it daily not only daily but about</i></p>
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				three times, each shift if someone had mouth care or what their tongue looked like so we would do that every day something that we are very aware of.' H4
Effects on oral health	Oral symptoms	<p><i>'I am getting dry mouth now even though I am drinking but I think that is again because of the tablets I am on.'</i> P1</p> <p><i>'Do you struggle to speak or to talk?'</i> No, not really just gets... I get trouble with people understanding.' P2</p> <p><i>'Only solid stuff. Can't eat anything solid.'</i> P2</p> <p><i>'Yeah very dry.'</i> P4</p> <p><i>'Hmm they're not too bad really. I have been having problems with a crown up here I had for many years a plate, an expensive plate it cost me £3000 hmm which caused all these teeth here and I always used to wear it, but because I have been sick lately I've not had it in.'</i> P4</p> <p><i>'No not very well I can taste it then I get one hit at the beginning and it's like oh it's nice and all of the sudden blurr dies off a bit.'</i> P4</p> <p><i>'Not really. I haven't been eating as much. Appetite has not been good anyway.'</i> P4</p>	<p><i>'Sometimes he fancies things and he doesn't want it, it doesn't taste right, things taste very sugary to him at times.'</i> R2</p> <p><i>'She couldn't wear them properly. Ok They must have been too loose because they were falling off her mouth when she was trying to eat.'</i> R3</p> <p><i>'I think she's got upper dentures and lot of people, I didn't realise but a lot of her friends didn't realise that she's got dentures. So it shows how much she wore them all the time. Now they don't fit quite properly so she's taking them out quite a bit.'</i> R4</p> <p><i>'So now she's finding it that a bit difficult, trying to speak without upper dentures in but hmm regarding the care they're brilliant.'</i> R4</p> <p><i>'So I think the thrush it has affected her taste buds and how she's perceived food. Actually I would really fancy that but when it comes to eat it, it doesn't taste right.'</i> R4</p>	<p><i>'And sometimes the patient will mention that possibly they've got sore mouth, ulcers, it doesn't feel right to them like it normally would in a normal person as well.'</i> H1</p> <p><i>'But if they have family members yes it will be mentioned that they've got coated tongue, their teeth are not looking so good, you know.'</i> H1</p> <p><i>'And also if their dentures don't fit they get a bit concerned about their dentures not fitting you know? And what can we do to help with that.'</i> H1</p> <p><i>'Yeah, obviously we are very conscious of ulcers.'</i> H2</p> <p><i>'Their mouths can be very dry, with thrush, tongue can be quite coated. It depends on the palliative case side you know? How poorly they are.'</i> H2</p> <p><i>'They might be concerned if the person is known to have some oral candida cause a lot of our patients get that and hmm or if it's very dry or maybe if the patient is not wearing dentures at the moment and is seen without them or so you know that sort of thing and yeah...'</i> H3</p>

	Exacerbating factors	<p><i>'Well before I used to use mouthwash but again it just the thought of having mouthwash hmm I just feel it would dry out my mouth a lot. So I haven't used that.'</i> P1</p> <p><i>'So I bought some colgate and only put a tiny amount now because it seems to dry mouth even more and also because it doesn't matter about my diet anymore I am eating a lot more sugar. So I try at least rinse my mouth well, brush my teeth in the morning and definitely brush my teeth at night time but only with a very small amount of toothpaste because it seems to dry my mouth out... yes'</i> P1</p>	<p><i>'She's had thrush for a little while, once her immune system started to get low and she's had various treatments for that, which I think to start with she wasn't doing it regularly enough, because she had a lot of medication and to do this 4 times a day on top and she is not a pill taker.'</i> R4</p>	<p><i>'It is not often that a patient will come into us and that their mouth... It might be quite clean but is not often that you get a lovely pink, clean, moist mouth. That doesn't happen very often... lots, lots of reasons a lot of it is drug induced yeah that doesn't happen very often. There is more often than not there is a bit of an issue with their mouths when they come in.'</i> H3</p>
	Everyday relieving factors	<p><i>'When I wake up in the morning my mouth is very dry and I have to have a good drink of water'</i> P3</p>	<p><i>'No no pain, but he just likes to keep it moist, that's it he is always sipping water more than he eats so...'</i> R2</p> <p><i>'I used to give him plenty of fluids, plenty of fluids again would give him plenty of fluids'</i> R2</p>	<p><i>'And we have lovely ice chips making machine which is wonderful. You know small ice chips and sometimes just a couple of those particularly if the tongue is really crusted or the lips are really really dry. You know the corners can get cracked don't they? It just it's just something extra we can do. Is just another way of getting fluid and that's a bit more comfort to try and help, you know lift whatever is on their tongue or to reintroduce them to fluids if they haven't been drinking.'</i> H2</p>
Enablers and barriers to oral care	Attitudes	<p><i>'Well I have always liked to look after my teeth because I have always had quite straight teeth.'</i> P1</p>	<p><i>'Because that's not a priority for her, she is so ill. Why bother? I think the only thing that would worry her would be having a smelly breath or something.'</i> R1</p>	<p><i>'Hmm I find it challenging more when the patient is not complying, declining care, because they just don't want it or hmm that they are really uncomfortable and nothing we</i></p>

		<p><i>'Nooo not really. Mouth is mouth teeth are teeth. I don't know' P2</i></p> <p><i>'But that gives me a good impression hmm I have got teeth and it helps me smile more you know?' P4</i></p>	<p><i>'It is quite difficult to brush someone else's teeth even when you are a parent to a child it is quite difficult. And you don't want to hurt them, you don't want to hurt their gums.'</i> R1</p> <p><i>'Said it was important to look after your... no it was the district nurses. They said it was important you must look after your teeth because that's the start point of our health.'</i> R1</p> <p><i>'Yeah yeah I think with her it does make a difference. She's always been very well turned out shall we say, her hair, manicure.'</i> R4</p>	<p><i>can do... no tools in the box you know? It think that's what I find more frustrating when you know those mouths are painful to swallow or whatever and you try to use you know...frequency of fluids and offering ice chips...trying to help dry mouth and you've offered all the sprays and the gels and nothing helps that's frustrating cause you want to help and you don't know what to do.'</i> H3</p> <p><i>'If they are conscious they'll feel... I mean 99% of people like having their mouth done don't they? It feels fresher. Sometimes if people are unconscious can clamp on the swabs so then you just wait for them to open their mouth and you would stop doing it and maybe doing it around their teeth rather than across their tongue and then sometimes you might go back and they may be alright with you doing it. So it's not set in stone. We don't say ohh they don't like having their mouth done. They may not like having their mouth done at that time but they might have it done before and that's because they are unconscious and may be thinking what's going in my mouth? What's happening? So it's more that really... Hmm When you have been lying and settled and someone does that yeah (laughs). But most people tend to... they prefer a mouth that's lubricated than dry, wouldn't they? So most people are happy for us to do it.'</i> H4</p>
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				<i>'But you have to because every patient is different so you know you can't just have one rule for all because not everybody does the same routine, do they?' H4</i>
	Training, guidelines and advice		<p><i>'Because that was always about him. We never had any input from health professionals other than us making appointments. It is only recently that she is in a place like this and had cancer that people started to be involved and someone mentioned teeth care and I think it was one of the [REDACTED] staff.'</i> R1</p> <p><i>'When they said about those sponges I had never heard of them so that came quite late. I think the oralieve would have been useful perhaps a bit earlier to keep her mouth fresher and that was one of the night sitters.'</i> R4</p>	<p><i>'It is it is, there isn't an awful lot. I couldn't find mouth care when I was last looking. There is a lot about xerostomia in patients having chemo, but when it gets to here, no there isn't. There isn't anything new that I'm aware of. I couldn't find anything, it doesn't mean it isn't out there.'</i> H3</p> <p><i>'Yes that is a good question! I am sure there are always things you can do to improve. A lot of it is preventative as well isn't it? To prevent problems in the first place. I suppose just keep educating the staff about recognising problems. Sometimes for example people can be getting oral thrush it is hard to be sure that they have got it until you look again the next day. Yeah try to get in earlier with treatments. I'm sure there is but I can't think of anything specific at the moment.'</i> H3</p> <p><i>'When I first started I'd never done mouth care before so it would be the staff nurses that would teach how to do it and then show you and then you would do it yeah'</i> H4</p>

	Learning from experiences		<p><i>'Only except when patients used to get thrush, they need medication for that. That's the one thing we used to look after. So you were aware of that? Mainly doing dressings, mainly. Oh that was during your professional life? Yes yeah' R2</i></p>	<p><i>'Yeah you can normally tell by their faces because they are either raising their eyebrows or shut their mouths. If they don't like anything they will actually shut their mouths. Or hopefully raise their eyebrows to say...' H1</i></p> <p><i>'Is there anything that you think do you think is there something that would improve your skills or confidence in providing mouth care or you don't think... I'm personally quite happy I've got so many years on the stroke ward the SALT team and hmm I personally haven't no.' H2</i></p>
	Access to dental professionals	<p><i>'The bottom ones are alright not too bad hmm I used to have a private dentist so I find it difficult now even to get to the dentist, that's the problem.' P4</i></p> <p><i>'Not not necessarily going to the dentist cause someone could visit me you know. That would be helpful having a home visit or something yeah' P4</i></p>	<p><i>'I think she thinks it's ok, that's healthy, she goes to the dentist regularly, in fact very regularly. I think she thinks it's ok.' R1</i></p> <p><i>'Now at the moment she could do with a massive hygienist session...' R1</i></p> <p><i>'No she wouldn't (laughs) I had never seen her without her teeth before. A bit of a shock, but as you get more poorly the less you care, don't you? But I think it does bother her that they don't fit properly now. Because she lost so much weight they rattle about so much. She has taken them out today. She is having trouble speaking. She says "I need to the dentist".' R4</i></p>	

	Fatigue		<p><i>'And brushing your teeth in the morning she would be tired because she would have eaten her breakfast which for her was a lot to do. So she would be tired at that point. So she would probably forget in the morning. More likely at night because she had bedtime routine. Ok. But she was absolutely shattered at that point, so it was minimum.'</i> R1</p> <p><i>'Not painful just hasn't the stamina, his stamina has gone and everything. He just didn't want to be fussed around.'</i> R2</p> <p><i>'He could do a little bit yeah... yeah he gets tired very tired.'</i> R2</p>	<p><i>'Sometimes because they are really at the end of their lives, so they find it a struggle. They get fatigued by cleaning their teeth. Sometimes they can't be bothered to do it because they are too tired so they need an awful lot of persistence with mouth care.'</i> H1</p> <p><i>'Yeah I can't think of any other specific thing. There are certainly challenges in palliative care yeah often fatigue, that's a huge one for our patients. Just can't do it, can't be bothered with it, too tired, don't want it or vomiting you know? Mouth dry and painful and you can't work you just can't relieve it. These are the main things I can think of at the moment.'</i> H3</p>
<p>Participants:</p> <p>P1- P4: Palliative care patients;</p> <p>R1-R4: Relatives;</p> <p>H1-H4: Healthcare professionals.</p>				

Table 9: Contribution of participants to themes and sub-themes

Themes	Sub-themes	Contribution of participants		
		Palliative care patients	Relatives/carers	Healthcare professionals
Performing oral care	Oral care by self	X	X	X
	Oral care by others	X	X	X
Effects on oral health	Oral symptoms	X	X	X
	Exacerbating factors	X	X	X
	Everyday relieving factors	X	X	X
Enablers and barriers to oral care	Attitudes	X	X	X
	Training, guidelines and advice		X	X
	Learning from experiences		X	X
	Access to dental professionals	X	X	
	Fatigue		X	X

Performing oral care

Participants described a range of oral care procedures and within this theme the researcher identified procedures done by the patients themselves i.e. 'oral care by self' and procedures done by others, i.e. 'oral care by others'.

The four palliative care patients interviewed were still able to do a little for themselves. This may explain the reason why they did not appear to contribute much to the sub-theme 'oral care by others'. Their only contribution was from patient3, stating that dental professionals, when they were at home, were looking after their teeth.

'Hmm and when you were at home. Were you looking after your teeth at home? Yes doctor [REDACTED] at Bovey Tracey was my dentist.' P3

Palliative care patients were able to describe what they were doing in terms of their self-care and this consisted mainly of brushing their teeth.

'I brush my teeth every day anyway should be more than once, I just get one set of teeth so once I just brush them down at the bottom. So yeah I brush them everyday and use a little pick thing to any bits of orange juice between my teeth because there are gaps there. Obviously other than that I do it all myself.' P4

The relatives not only described how their loved ones looked after their teeth and mouths, but also how they cleaned their dentures. These participants described the oral care procedures with more detail than patients.

'I know she used sensodyne for ever and she has an electric toothbrush but whenever I heard it, it's not long enough.' R1

'Hmm she used to soak her denture in cold water and think she had sterodent at home in the bathroom cabinet, so I presume she used sterodent to brush her teeth. That's all I can say I'm afraid.' R3

In addition, relatives considered that 'oral care by others' was provided by dental professionals, HCPs and themselves.

'But luckily she has had a dentist that has seen her regularly and maybe kept her on track.' R1

HCPs seemed keen to encourage patients to remain independent. Therefore, if they were still conscious and able to do a little, they would encourage them to continue to brush their own teeth, albeit with some support, if required.

'Yeah yes if they are able to then we would encourage them to carry on doing that or if they are capable of cleaning their teeth but they need the equipment put together for them then the nurses would do that, but also when they're having you know, it usually happens in the morning, bath or shower, it's usually at that time or after meals.' H3

HCPs seemed to adapt the oral care provided according to the patients' needs and their own routine. The oral care would differ if a patient was conscious and independent or if a patient was unconscious and near the end-of-life. In addition, patients' preferences were taken into account.

'If they are conscious, we would do it as if you were at home, morning and night. But if they said would you mind brushing my teeth now, then we would and we would clean their dentures if they didn't feel up to doing that. If they're unconscious we would do it as much as needs be. So it isn't always set in stone... It's whatever the patient needs. If someone has a really dry mouth we would be doing it more regularly than if someone whose mouth isn't that dry. It's not a steadfast rule how often we do it to accommodate the patient.' H4

'If someone was unwell and was unconscious then we would set up a mouth care tray and there we have mouth swabs, mouthwash if a patient likes mouthwash, sometimes you put alcohol, if they like the taste of alcohol or water, so we would go around their mouths with a mouth swab or brush their teeth before if they are up to that. Going around with the mouth swabs and sometimes we use something called biotene or oralieve mouth gel so we would use that to go around and then vaseline on their lips as long as they aren't on oxygen. So so we are quite adaptable to what someone wants. If someone didn't like mouth care we would stop doing it and then we would go back, say in a quarter of an hour and say... because it's quite invasive, people are unconscious so...' H4

Furthermore, the oral care performed by patients or delivered by others was also to address specific oral symptoms such as xerostomia.

'They gave him a mouth spray, because when he came in he said it was dry. Don't think he uses it that much, don't know it's on top of his table. I don't know because he just keeps eating ice, they give him broken ice...' R2

HCPs were the only group that provided great detail on oral care procedures. The hospice where they work and where the interviews took place has its own standard operating procedures for oral assessment of patients and protocols for oral care.

Effects on oral health

This theme is about the oral symptoms experienced by palliative care patients and observed by their relatives and HCPs. Dry-mouth or xerostomia was a common complaint by patients.

'Feels drier I think. I suffer from a dry mouth.' P3

'I think it is more his mouth than his teeth if I'm honest. Hmm... it gets very dry very dry' R2

'Their mouths can be very dry, with thrush, tongue can be quite coated. It depends on the palliative case side you know? How poorly they are.' H2

However, participants reported other oral symptoms such as mouth ulcers, thrush, difficulty in communicating, difficulty in swallowing, not being able to taste and also problems with dentures.

'No, no it was all about the plate. But I know the furry tongue still bothers her so it would have been nice to have cleaned it. Other than that I can't really think about anything else with her mouth really.' R4

The medication and their illnesses were exacerbating factors to oral symptoms.

'I just get a little bit of jaw ache because of the steroids I am now on but it has calmed down... it is basically a little bit of jaw ache but I think that is because of the steroids because when you first go on steroids it feels like your mouth is going to collapse and they do say if you are on steroids for a very long time then your bone structure starts to collapse but I am not on a huge amount of steroids heah I can feel my teeth if... I grind my teeth when I sleep.' P1

There were simple, everyday measures, such as drinking water and ice chips, that patients tried in order to alleviate oral symptoms. Despite its everyday nature, these measures appeared to be promoted by HCPs and recognised as being helpful by all participants.

'it gets very dry very dry and keeps having pieces of ice and things that are cold. He seems to enjoy it, seems to help the dryness.' R2

Enablers and barriers to oral care

All the sub-themes, 'attitudes'; 'training, guidelines and advice'; 'learning from experiences'; 'access to dental professionals', within this theme except for the last one, 'fatigue', were viewed as both enablers and barriers.

The attitude towards oral care varied amongst the participants. Oral care was being done by the patients interviewed. However, it seemed, particularly with patients2 and 3, that it was not a priority. The HCPs at the hospice would encourage patients to brush their teeth so they did so. Nevertheless, oral care was often not important for patients.

Patient2 recognised that he did not have long to live.

'No not difficult (coughs). The nurses remind me to do me teeth (both laugh)' P2

*'At the moment it is not important. I couldn't care less. **No I do understand that. It may seem quite an obvious question to me but may I ask you why? Why you couldn't care less? Because I am on me way out**'* P2

Patient3 on one hand appeared to acknowledge the association between good oral health

and general health. Yet, it was no longer a priority, he was nearly 90 years old after all.

'Hmm do you worry about how your mouth and your teeth look like? A little bit, but I am getting past it. I am nearly 90 (both laugh)' P3

'Well if you got a clean mouth all being well you got a clean inside as well' P3

Nevertheless, patients 1 and 4 seemed to prioritise oral care and the benefits associated with it, particularly in social interactions and for their own psychological wellbeing.

'it is a good idea to take care of your teeth (coughs) because apparently it is very painful when they go wrong like I had a root canal once it was so painful so I just had my tooth taken out. So I have always looked after my teeth I have always gone to the dentist every 6 months, wore a nightguard, because I used to grind my teeth quite a lot. So no to me is important. And also you just like to have your mouth as fresh as possible as well. Because people always seem to judge you. You know when you smile they say... it is always nice to have a good smile. So to me oral health has always been important.' P1

'Yeah oh yes I think it is always important to have a pleasant oral appearance about yourself you know fresh teeth and fresh breath. You know yeah you are breathing down on people.' P4

Relatives and HCPs seemed to share the view that for patients, oral care was often not a priority. All HCPs interviewed valued and prioritised oral care. This was despite some HCPs recognising an improvement on oral health was not always achievable. Some patients were very poorly and at the end of their lives and compliance with oral care was difficult. Nonetheless, for HCPs interviewed, oral care was an important part of holistic care. This is the ethos of palliative care.

'I don't think we are going to improve the oral health of our patients because a lot of our patients are coming here are actually end of life. They are not what I would call ordinary day to day patients so we are not actually going... we could improve it but obviously the medication etc. but it doesn't always work with every patient. But we try our hardest to get on top of some of the thrush etc. but more or less we don't improve patients' mouths if you are an end of life unfortunately. Ordinary patients they yes we would try to improve it but obviously in patients like we have they might only have a couple of weeks left to live and that's not their top priority at that time.' H1

'And when you are unwell maybe even more so, do you know what I mean? If your mouth is healthy I mean it's as important as other nursing care that we give. Yeah.'
H4

One of the relatives interviewed questioned her own attitude and society's attitude towards individuals who are at the end of their lives. It is about the person's dignity and it does not end when one becomes unwell.

'It is this attitude we have towards people that are ill, but if they have another week we should try to make them more comfortable. The perception is oh never mind for example you can manage without the denture, but they are managing with so much already, perhaps getting the dentures more comfortable, if it is possible, I don't know whether it is feasible... I could take them in... I don't know whether she would want the hassle now, but I could ask her. She was all about appearance but now that she's got so poorly, I think we perhaps got beyond that stage.' R4

In addition, relatives reported lack of knowledge and professional advice which added difficulties to performing oral care. HCPs stated the lack of guidelines available.

However, they felt confident on their skills. HCPs appeared to recognise how the hospice setting with its in-house training, more time for personal care and availability of different products, was conducive to a more patient-centred approach to oral care.

'No we do it in house. In house training and also they brought two new sets of swabs out as well. One that has actual toothpaste in the swab and one that hasn't as well. So...' H1

'It was lovely to come here and to see and have all these products available whereas on the ward NHS or at the time, hopefully it has changed but at the time we only had the pink swabs and Vaseline and the glycerine like a lollipop glycerine thing. I personally never had very good results with it. So it's nice to come here and with the toothpaste it is like uau I have not seen that and we also have the oralieve not foaming toothpaste which is brilliant because if they don't have the strength to spit it out they don't have to so there's no foam there and they've got this nice fresh mouth.' H2

'Yes more than you would have in the hospital yeah and with palliative care patients things like mouth care and other types of care are very important so you know we are not doing obs every quarter of hour or something like that. We would be doing something like mouth care. So you are just... this is what we do, so that's probably why and we have the time. And spend the time with patients we are able to talk to

them and I suppose know what they want. Most of our patients need some hand with personal care whereas in hospital if you are quite well you might go off and wash yourself and I wouldn't know that you don't like toothpaste or that you like toothpaste so I suppose it's just the nature of the care that we give really being palliative care so... ' H4

Furthermore, to the training and advice on products, HCPs seemed to rely on their own professional experience and shared experience from colleagues. They either had been performing oral care for palliative care patients for a long time, or they had been supported by other team members at the hospice. Only one relative mentioned previous professional experience as an enabler to helping with oral care.

'So no I haven't had specific training myself not since I was a student nurse. Hmm in those days god we used to have the metal forceps and we used to have gauze and have to have it around and you were not allowed to touch it. All nervous and dropping it. Oh it was dreadful (laughs)! I can remember! But no it's the stuff I have researched and that we do here. So hopefully we get it fairly right I don't know we can only try and find information you are able to find.' H3

Having access to dental professionals was considered a challenge by some patients, particularly due to the fact of being in a hospice. It would be helpful to be able to see a dentist to help with certain oral symptoms, particularly difficulties with dentures. In addition, relatives also seemed to recognise that their loved ones needed to see a dentist or a hygienist to improve their oral health. HCPs were the only participants not to have contributed to this sub-theme (Table 9).

'Not not necessarily going to the dentist cause someone could visit me you know. That would be helpful having a home visit or something yeah... It's always helpful when you are at a disability stage in a wheelchair you can't just get out as much or when you do it becomes a bit more difficult. Yeah a home visit I know again I think there are things like that in the pipeline anyway.' P4

'I think she thinks it's ok, that's healthy, she goes to the dentist regularly, in fact very regularly. I think she thinks it's ok.' R1

Fatigue was a very 'loud' sub-theme and it is the only one within this theme that is clearly a barrier and not an enabler. Relatives and HCPs mentioned patients were too fatigued, they could not be bothered with oral care. There were other priorities to save their energy for or it was not important anymore. The patients interviewed did not express themselves on the issue of fatigue. Nevertheless, the interviews were typically short as the interviewer was alert and responsive to signs of fatigue. The interview with patient2 lasted just over 8minutes and with patient3 just over 6minutes. The average of all twelve interviews conducted was over 16minutes. In addition, the following extract of the researcher's field notes, following the interview with patient2, indicates awareness of and sensitivity to the impact of fatigue on data collection.

'I just wanted to leave and stop the interview. I just wanted to leave you in peace and not disturb you any further... you are obviously struggling to talk... you need to rest.'

4.5 Discussion

Following the analysis of the data from the interviews, the researcher identified three themes: 'performing oral care', 'effects on oral health' and 'enablers and barriers to oral care'. The identification and interpretation of these themes contributed to the understanding of the essence of the phenomenon being studied: the participants' experiences of oral care. As stated previously, the essence of a phenomenon is what makes the phenomenon what it is, it is its essential meaning (Dahlerg, 2006). In this study, the essence of the participants' oral care experiences is presented in Figure3.

Palliative care patients who were able to carry out self-care mainly brushed their teeth and looked after their dentures. Other care tended to be carried out by relatives and healthcare professionals (HCPs); and it was often adapted based on a person's level of consciousness. When describing the specific effects of poor oral care on oral health, relatives and HCPs tended to focus on dry mouth, whereas patients provided detailed accounts including difficulties with swallowing, taste and communication. Their descriptions were often vivid e.g. 'feels like your mouth is going to collapse' (effect of steroids an exacerbating factor) which highlights the psychological and social impact of oral symptoms.

Thus, was oral care seen as a priority? For patients this varied, with some acutely aware of the knock-on effect for wellbeing and others downplaying the importance in relation to other aspects of illness and the end-of-life process.

Relatives and HCPs shared the view that oral care is a priority and an important component of holistic person-centred care. For them the impact of care related to dignity and comfort. Although HCPs and relatives relied on valuable past experiences of caring, both groups perceived that education and training were lacking. Patients reported a lack of access to dental care in the hospice setting. One of the biggest barriers to self-care or other oral care was patient fatigue: a barrier that relatives and HCPs found extremely hard to overcome.

Figure 3: The essence of the participants' oral care experiences

Relatives and HCPs appeared to agree that oral care was not a priority to palliative care patients. They were simply too fatigued and overwhelmed by all the other aspects of their illness. It is recognised that oral symptoms are often underreported by patients and that HCPs do not assess the mouth as well as they assess other parts of the body (Wilberg *et al.*, 2012). In addition, and as described with the study of blogs and discussion forums, presented in chapter2, oral care is often overlooked until the

individual's quality of life becomes compromised by oral symptoms (Bernardes Delgado *et al.*, 2018).

In this study, oral care was a priority for some palliative care patients, and it was not for others. Therefore, the importance of oral care for patients, did not seem as clear as relatives and HCPs perceived it. Indeed, two of the four patients interviewed, were too tired and the interviews were very short. However, the other two patients valued oral care, and this was not simply to address oral symptoms. It was also to do with their social interaction with others and their self-esteem. Indeed, other authors report the social and emotional impact oral problems have on palliative care patients (Rohr, Adams & Young, 2010).

HCPs often consider delivering oral care an unrewarding task and the main objectives are comfort and cleanliness (Croyere *et al.*, 2012). Nevertheless, some of the more vivid descriptions by patients of oral symptomology in this study, related to the enormous psychological and social implications of not being able to taste, swallow and communicate. As stated in the conclusions to the systematic review described in chapter3, if HCPs were more aware of the impact of poor oral health, perhaps they would find providing oral care rewarding. Indeed, the HCPs interviewed acknowledged the importance of good oral health and perceived oral care to be an invaluable part of holistic care. One could argue that understanding the wider implications of poor oral health to patients and the known benefits of oral care, should be an important component of HCPs' training. In addition to involving dental professionals in the care of these individuals, as defended by some authors (Saini *et al.*, 2009; Wilberg *et al.*, 2012).

Access to dental professionals was a barrier to oral care identified in this study.

Palliative care patients and their relatives recognised the importance of accessing professional dental care and the challenges of doing so while staying in the hospice. Despite everyday oral care measures being recognised as effective to address oral symptoms by all groups interviewed, there was also the understanding certain oral complications, such as ill-fitting dentures, required professional care. This finding is comparable to other studies that state dental services are necessary in the care of palliative care patients (Lee *et al.*, 2001; Ohno *et al.*, 2016).

Despite the differences stated above, and contrary to the findings of the review described in the previous chapter, the HCPs interviewed seemed to value above all a holistic, patient-centred approach to care. The oral care provided was viewed as an essential component of caring for palliative care patients. In addition, there was not a one measure fits all approach. The oral care provided was dependent not only on the individual's level of consciousness but also on patient's preferences.

Furthermore, given the setting HCPs were working in, they felt they had the time, resources and adequate in-house training to provide good oral care. This is in contrast with other studies, in which authors stated staff pressures, time pressures and inadequate training as barriers to oral care to palliative care patients (Aldred *et al.*, 1991; Kvalheim *et al.*, 2016). The hospice where the interviews took place has a standard operating procedure for oral assessment of patients and oral care protocols. This is relatively rare as discovered through a survey of oral care practices conducted by the Multinational Association of Supportive Care in Cancer (MASCC) and the International Society for Oral Oncology (Barker *et al.*, 2005).

Although, HCPs felt confident in their skills, they perceived evidence-based education and training on oral care as lacking. They had either been performing oral care for palliative care patients for a long time, or they had been supported by other team members at the hospice. Similarly, relatives also perceived education on oral care as lacking and a forgotten aspect of care. This aspect seemed important while their loved-ones were being cared for in the community and not as in-patients at the hospice. At the hospice, oral care was delegated to HCPs, who relatives perceived as doing a brilliant job.

Nevertheless, patients' fatigue was a barrier difficult to overcome by HCPs and relatives. Indeed, it seemed that these two groups perceived fatigue as the biggest barrier to oral care. Fatigue and pain have been reported as the most prevalent and distressing symptoms for palliative care patients, with a cancer diagnosis, who are receiving end-of-life care (Omran, Khader & McMillan, 2017). Therefore, it is not surprising that fatigue seemed to be so prevalent amongst patients in the hospice, who themselves had a cancer diagnosis. Continuity of care is argued as being vital in developing interventions to improving symptom management, such as fatigue and pain (Skrutkowski *et al.*, 2008). However, it was outside the scope of this study to assess this aspect.

4.6 Limitations

In order to evaluate the worth of this study, it is important to assess the trustworthiness of its findings (Lincoln & Guba, 1985). Credibility, transferability, dependability and confirmability are the criteria used to assess trustworthiness of findings.

Data on palliative oral care is scarce and one could posit that this is in part since data is difficult to access, and this is a difficult group to identify and reach. Hence, the researcher attempted to overcome this difficulty by interviewing participants in a hospice. Nevertheless, not all palliative care patients need to be cared for in hospices. These individuals, as acknowledged by staff at the hospice, tend to be those with poorly controlled symptoms or receiving end-of-life care. Most palliative care patients are cared for in the community. Despite the researcher providing a description of the setting and participants, this is a limitation and can impact on the transferability of the findings from the study.

In addition, the researcher did not check her analysis with participants, i.e. member checking. This was to avoid burden participants. Other techniques were employed to ensure credibility of findings. The researcher spent a prolonged period of time in the hospice before interviews took place. A second experienced researcher reviewed the data analysis and interpretation. This was not to achieve consensus but to view the data from a different perspective and access its essence. Furthermore, the reviewer attempted to attain confirmability of findings by making it clear and transparent that the findings derived from the data and could be trusted.

Nevertheless, one could argue that the participants interviewed were not as diverse as initially anticipated. The researcher aimed to interview cancer and non-cancer patients, however all patients interviewed had a cancer diagnosis. It is recognised that cancer patients have a more predictable trajectory to their illness, making it easier to plan for their needs (WHO, 2004a). This may explain why most in-patients had a cancer diagnosis.

Finally, the patients interviewed were very frail and fatigued. Therefore, three of them had to be interviewed in bed. This created problems with privacy as they shared a room with other patients. It is not possible to assess the impact this had on what was said during the interviews.

4.7 Conclusion

The findings of this study contributed towards understanding the essence of the oral care experiences of the participants interviewed.

HCPs perceived oral care as an essential part of holistic care and took a patient-centred approach to oral care. They were confident providing oral care and felt they had the resources and time to do it well. They acknowledged that evidence-based training and resources were lacking. It appears that the care provided to patients was based on the following principles of evidence-based medicine: patients' preferences and values; knowledge, experience and skills; and the best available evidence (Collins, 2007). The best available evidence was mainly based on expert opinion. Nevertheless, the hospice had procedures and protocols in place to provide guidance to staff and ultimately to deliver better care. Relatives perceived the care their loved-ones received at the hospice as being excellent. This included oral care. They too acknowledged that education and training in oral care was lacking. This was particularly noticeable when patients were being cared for in the community.

All groups recognised the effects of poor health, namely dry-mouth and problems with dentures. Nevertheless, patients also presented vivid descriptions of the impact oral symptomology had on their ability to taste, swallow and communicate. Accessing dental

professionals was considered a barrier while staying in the hospice and it was perceived as a way of overcoming some dental problems, namely with dentures. Finally, fatigue was recognised as the major barrier to oral care by HCPs and relatives.

Despite the limitations of this study, some of these findings may have implications to practice and education such as, facilitating access to dental professionals while patients are at the hospice; educating HCPs to the wider impact of oral symptoms to patients; and given that fatigue has such a big impact on the acceptability of oral care from palliative care patients, developing interventions to overcome or minimise fatigue in the delivery of oral care. The dire consequences of poor oral care on oral health and ultimately on physical and psychological wellbeing, particularly of medically-compromised and frail individuals, makes oral care even more relevant.

CHAPTER 5: Conclusions

5.1 Summary of findings

The aims of this research project were to explore and better understand the oral care experiences of palliative care patients; and the oral care experiences of their relatives/carers and HCPs.

In order to achieve these aims the researcher conducted three studies: a study of blogs and discussion forums, followed by a qualitative systematic review and finally an interview study in a hospice in the South-West of England.

These three studies provided insight into a poorly researched topic and enabled the researcher to access what the oral care experiences of palliative care patients, relatives/carers and HCPs may be. The theoretical approach adopted throughout this thesis recognises that not only knowledge of reality is mediated by individuals' perceptions, but also there are valid alternative accounts of a phenomenon. Therefore, equal value was placed on the accounts of patients, relatives/carers and HCPs.

The findings from the study of blogs and discussion forums were limited, and with this study the researcher only accessed the perspective of relatives, some of which were also carers to palliative care patients. The thematic analysis process of the study of blogs and discussion forums identified three main themes: 'symptoms', 'procedures' and 'emotions'. The blog authors described oral symptoms that they could observe themselves and perceived as being distressing to their relatives. There was an association between oral care procedures and the oral symptoms observed. However, routine oral care procedures were described without much detail. When negative events happened there was a much more in-depth and emotionally charged description. The

blog authors' emotional responses to the oral care delivered and/or lack of oral care delivered, varied between anger, guilt, worry and trauma. These emotions were interconnected to the context in which the reports took place and how the relatives felt about what was happening to their family member. Most palliative care patients mentioned were terminally-ill and the deaths of ten were recounted within the blogs and discussion forums.

Subsequently, a qualitative systematic review was conducted. With this study it was possible to start understanding what the oral care experiences of not only relatives/carers, but also palliative care patients and HCPs may be. Three themes were identified from the data: 'performing oral care', 'effects on oral health' and 'challenges in palliative care'. All groups shared a similar view regarding 'performing oral care'. They did not provide much detail regarding oral care procedures, but comfort and cleanliness seemed to be the ultimate goals of performing oral care. Palliative care patients described not only the oral symptoms they were experiencing, but also the wider impact these had on their quality-of-life, namely the psychological ramifications of not being able to talk or eat. Relatives and HCPs did not seem to be aware of the wider implications of poor oral health. In addition, the challenges experienced differed between the three groups. Palliative care patients experienced loss of independence and unmet needs, relatives experienced negative feelings about the oral care provided to their loved ones and HCPs were confused regarding what oral care to provide and where to look for advice. Moreover, HCPs seemed to perceive oral care as an unrewarding task, which appears to demonstrate that they were not aware of the enormity of the consequences of poor oral health to palliative care patients. In addition, HCPs did not take a patient-centred approach to timing to provide oral care.

Finally, the researcher interviewed palliative care patients, relatives and HCPs in a hospice in the South-West of England. Analysis of the data from the interviews, generated three themes: ‘performing oral care’, ‘effects on oral health’ and ‘enablers and barriers to oral care’. These contributed to the understanding of the essence of the phenomenon being studied: the participants’ experiences of oral care. Palliative care patients who were able to carry out self-care mainly brushed their teeth and looked after their dentures. Relatives and HCPs carried out other care, which was adapted based on person’s level of consciousness and preference. When participants described specific oral symptoms, relatives and HCPs tended to focus on xerostomia, whereas patients provided detailed accounts including difficulties with swallowing, taste and communication. Regarding the importance of oral care, for patients this varied. Some seemed very aware of the consequences of poor oral care on their wellbeing and others downplayed the importance of oral care in relation to other aspects of illness and the end-of-life process. Relatives and HCPs shared the view that oral care was a priority and an important component of holistic care. Although HCPs and relatives relied on valuable past experiences of caring, both groups perceived that education and training was lacking. Patients reported a lack of access to dental care in the hospice setting. One of the biggest barriers to self-care or other oral care was patient fatigue. This was a barrier that relatives and HCPs found exceptionally hard to overcome.

Overall, in the three studies, oral symptoms were mentioned by all participants. However, the wider consequences of oral symptoms were not acknowledged by relatives or HCPs. The challenges of palliative oral care seem to be significant for both patients and those involved in delivering oral care to palliative care patients. Despite the challenges and barriers to oral care, such as fatigue, this research project also identified important enablers. It seems that when patients are being cared for in a setting that

prioritises holistic and person-centred care, oral care is recognised as an essential part of that care. In addition, HCPs seem to find oral care rewarding and relatives perceive the oral care provided to their loved ones as being excellent. It was possible to identify good practices on oral care from the interview study.

5.2 Limitations of the research

Having completed the three studies, it is now important to reflect on the strengths and limitations of the project.

The aim of this project was to explore the oral care experiences of three groups: palliative care patients, relatives/carers and HCPs. In addition, equal value was placed on these different perspectives. Nevertheless, the experiences of relatives and HCPs were overrepresented. The study of blogs and discussion forums only included relatives and HCPs were not only interviewed for longer, but the data collected was also richer and more in-depth.

The setting of the interviews was another limitation. All the patients interviewed had a cancer diagnosis and were frail. This impacted on the duration of the interviews and depth of the data. In addition, by conducting the interviews in a hospice, the researcher did not access the experiences of most palliative care patients, who are cared for in the community. All these aspects limit the transferability of findings.

The researcher disclosed to all interviewees her clinical background. It is possible that this affected data collection, as the researcher was also regarded by participants as a dental professional.

5.3 Recommendations for clinical practice and future research

A number of recommendations emerge from the findings of the three studies conducted:

- It was possible to identify good oral care practices in the hospice where the interviews took place. When the focus is on holistic care and HCPs feel they have time and support this leads to good examples of good oral care practices that can be learnt and transferred to other settings.
- There is the need for better engagement between hospices and NHS dental services that will enable a collaboration between dental and palliative care professionals. Access to dentists while patients are in a hospice setting seems to be very difficult. Similarly, to what happens with other individuals that need to be seen in their own homes or care homes and have access to domiciliary dental visits, patients who are in hospices should be able to access this service.
- Access to education and training on oral care by relatives and/or carers. This should include awareness raising of the social and psychological consequences of poor oral hygiene. Most palliative care patients are not in hospices. They are in the community, where relatives and/or carers, rather than healthcare professionals, are the main care providers.
- To conduct research that explores the oral care experiences of palliative care patients outside a hospice care setting i.e. in the community where most patients are cared for.
- To develop and evaluate an oral care intervention/ protocol for main care providers. Any such intervention should address the barriers to care that were identified with this research e.g. fatigue. There is a lack of evidence-based guidance on the oral care of palliative care patients.

Indeed, poor oral care can lead to very poor oral health which has dire consequences to already frail and medically compromised patients. This is a relevant topic that requires further study. As one relative put it: *'It is this attitude we have towards people that are ill... The perception is oh never mind... but they are managing with so much already.'*

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Terpenning, M. S., Taylor, G. W., Lopatin, D. E., Kerr, C. K., Dominguez, B. L. & Loesche, W. J. (2001) 'Aspiration pneumonia: dental and oral risk factors in an older veteran population.'. *Journal of the American Geriatrics Society*, 49 (5), pp. 557-563.

Thomas, J. & Harden, A. (2008) 'Methods for the thematic synthesis of qualitative research in systematic reviews.'. *BMC Medical Research Methodology*, 8 (45), pp. 1-10.

Tong, A., Flemming, K., McInnes, E., Oliver, S. & Craig, J. (2012) 'Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ.'. *BMC Research Methodology*, 12 (181), pp. 1-8.

WHO (2004a) 'Palliative Care. Solid facts.'. [Online]. Available at: http://www.euro.who.int/_data/assets/pdf_file/0003/98418/E82931.pdf (Accessed: 17/02/2020).

WHO (2004b) 'Palliative Care. Symptom management and end-of-life care.'. [Online]. Available at: <http://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf> (Accessed: 18/02/2020).

Wilberg, P., Hjerstad, M. J., Ottesen, S. & Herlofson, B. B. (2012) 'Oral health is an important issue in end-of-life cancer care'. *Supportive Care in Cancer*, 20 (12), pp. 3115-3122.

Wiseman, M. A. (2000) 'Palliative care dentistry'. *Gerodontology*, 17 pp. 49-51.

Wiseman, M. A. (2006) 'The treatment of oral problems in the palliative patient'. *J Can Dent Assoc*, 72 pp. 453-458.

APPENDICES

Appendix 1: Contribution to publication - Study of blogs and discussion forums

Plymouth, 8th October 2019

Contribution to Publication

Dear Lorna,

I am in the process of writing my ResM thesis and chapter 2 is a publication. The below joint paper will be included as part of my thesis. Can you please confirm that for the following publication my contribution was 90%?

Bernardes Delgado M, Burns L, Quinn C, Moles DR, Kay E (2018) 'Oral care of palliative care patients – carers' and relatives' experiences. A qualitative study.' *British Dental Journal* 224 (11) pp 881-886

Most Sincerely,
Maria.

Pleaser insert you signature:

A handwritten signature in dark ink, appearing to read 'L Burns', with a stylized flourish underneath.

Mrs Lorna Burns

Contribution to Publication

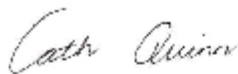
Dear Cath,

I am in the process of writing my ResM thesis and chapter 2 is a publication. The below joint paper will be included as part of my thesis. Can you please confirm that for the following publication my contribution was 90%?

Bernardes Delgado M, Burns L, Quinn C, Moles DR, Kay E (2018) 'Oral care of palliative care patients – carers' and relatives' experiences. A qualitative study.' *British Dental Journal* 224 (11) pp 881-886

Most Sincerely,
Maria.

Pleaser insert you signature:

A handwritten signature in cursive script that reads "Cath Quinn".

Dr Cath Quinn

Contribution to Publication

Dear David,

I am in the process of writing my ResM thesis and chapter 2 is a publication. The below joint paper will be included as part of my thesis. Can you please confirm that for the following publication my contribution was 90%?

Bernardes Delgado M, Burns L, Quinn C, Moles DR, Kay E (2018) 'Oral care of palliative care patients – carers' and relatives' experiences. A qualitative study.' *British Dental Journal* 224 (11) pp 881-886

Most Sincerely,
Maria.

Pleaser insert you signature:

A handwritten signature in black ink that reads "DR Moles". The letters are cursive and stylized, with the "D" and "R" being particularly prominent.

Professor David Moles

Plymouth, 7th October 2019

Contribution to Publication

Dear Liz,

I am in the process of writing my ResM thesis and chapter 2 is a publication. The below joint paper will be included as part of my thesis. Can you please confirm that for the following publication my contribution was 90%?

Bernardes Delgado M, Burns L, Quinn C, Moles DR, Kay E (2018) 'Oral care of palliative care patients – carers' and relatives' experiences. A qualitative study.' *British Dental Journal* 224 (11) pp 881-886

Most Sincerely,
Maria.

Pleaser insert you signature:

A handwritten signature in black ink that reads "Elizabeth Kay". The script is cursive and fluid, with the first name "Elizabeth" and the surname "Kay" clearly distinguishable.

Professor Elizabeth Kay

Appendix 2: Search history – Study of blogs and discussion forums

Search strategies targeted to the following sites using Google.co.uk:

**tumblr.com; medium.com; wordpress.com; squarespace.com; blogger.com;
wix.com; weebly.com**

(hospice OR palliative) ("dry mouth" OR "oral care" OR "sore mouth" OR mouthrinse
OR mouthwash) ("my mother" OR "my father" OR "my husband" OR “my wife”)

(hospice OR palliative) (mouth (wet OR water OR moisten) (sponge OR sip)) ("my
mother" OR "my father" OR "my husband" OR “my wife”)

Search strategies targeted to the following site using Google.co.uk:

community.macmillan.org.uk

(mouth OR oral (wet OR water OR moisten OR moist) (sponge OR swab)) ("my mum"
OR "my dad" OR "my mother" OR "my father" OR "my husband" OR “my wife”)

("dry mouth" OR "oral care" OR “mouth care” OR "sore mouth" OR mouthrinse OR
mouthwash) ("my mum" OR "my dad" OR "my mother" OR "my father" OR "my
husband" OR “my wife”)

hospice mouth (sponge OR swab)

Searches conducted on the 25/01/2017

Appendix 3: Demographic data - Study of blogs and discussion forums

Participant number	Country*	Blog/discussion forum	Author*	Description
1	USA	Blog	Female in her late 50's early 60's	The post on 29/05/2013 describes her father's experience in a hospice.
2	USA	Blog	Female in her late 50's early 60's	Blog giving advice/sharing experiences with people who care for Alzheimer's patients. Author's mum has Alzheimer's.
3	USA	Blog	Female in her early 50's	The post on 09/05/2015 describes the author's relationship with her grandmother and the grandmother's final days.
4	USA	Blog	Male	Son-in-law reports on his mother-in-law's last months and his and his wife's role as carers.
5	USA	Blog	Female	A daughter's reflection on her father's cancer journey, the lessons learned the grief process and the value of faith.
6	USA	Blog	Female	A daughter's reflection on her father's final days and the importance of her and her family's faith.
7	USA	Blog	Female	A daughter's reflection on her mother's final years and her role as a carer.
8	Canada	Blog	Female	A daughter's reflection on her mother's journey: from diagnosis of pancreatic cancer until her death.

9	UK	Discussion forum	Female starts discussion	Query from daughter whose father has throat cancer: “How long without water?”
10	UK	Discussion forum	Female starts discussion	Daughter worried that her actions might have contributed towards her father’s distress: “Lost my dad 3 years ago, worried about the way he died.”
11	UK	Discussion forum	Female starts discussion	Wife, whose husband is about to start intensive chemotherapy and radiotherapy, seeks advice on how to address the effects of the treatment. “Helping my husband.”
12	UK	Discussion forum	Female starts discussion	Wife of cancer patient describes a specific symptom, dry mouth, and how to address it. “Dry mouth.”
13	UK	Discussion forum	?	Author states the trauma of witnessing his/her mother painful death. “Can’t get over how mum died.”
14	UK	Discussion forum	Female starts discussion	Daughter provides an update on mother’s condition. “Mum has only days left now.”
15	UK	Discussion forum	Female starts discussion	Daughter wonders whether father is about to die. “Final stages?”

16	UK	Discussion forum	Male starts discussion	<p>Father, whose daughter died, describes chronologically his daughter's cancer journey.</p> <p>"Glioblastoma why why why."</p>
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*Information assumed from text references.

Appendix 4:**Adapted table – Enhancing transparency in reporting the synthesis of qualitative research: the ENTREQ statement**

Item	Thesis page number
1. Aim	51
2. Synthesis methodology	51
3. Approach to searching	53
4. Inclusion criteria	54
5. Data sources	56
6. Electronic search strategy	56
7. Study screening methods	56
8. Study characteristics	62
9. Study selection results	56
10. Rationale for appraisal	58
11. Appraisal items	58
12. Appraisal process	58
13. Appraisal results	60
14. Data extraction	59
15. Software	59
16. Number of reviewers	60
17. Coding	59
18. Study comparison	60
19. Derivation of themes	60
20. Quotations	58 – Table 5
21. Synthesis output	67

Appendix 5: Search histories – Qualitative systematic review

Palliative oral care 31/08/2017

Embase (Ovid)	1472
Medline (Ovid)	1117
DOSS (EbscoHost)	417
CINAHL (EbscoHost)	723
AMED (EbscoHost)	80
PsycINFO (NHS HDAS)	110
Total before deduplication:	3919

Embase <1974 to 2017 August 30>

Date searched: 31/08/17

#	Searches	Results
1	terminal care/	30520
2	palliative therapy/	69475
3	palliative nursing/	477
4	cancer palliative therapy/	20258
5	hospice care/	8333
6	hospice patient/	558
7	hospice nursing/	43
8	terminally ill patient/	7086
9	nursing home/	48165
10	nursing home patient/	4835
11	nursing home*.ab,kw,ti.	33756
12	(end* adj3 life).ab,kw,ti.	31578
13	(last year adj3 life).ab,kw,ti.	766
14	(terminal* adj3 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti.	15481
15	(palliative adj3 (cancer* or care or healthcare)).ab,kw,ti.	38207
16	(dying adj3 patient*).ab,kw,ti.	7877
17	(close adj3 death).ab,kw,ti.	684
18	(hospice* adj3 (care* or healthcare)).ab,kw,ti.	6964
19	end stage.ab,kw,ti.	82012
20	terminal stage.ab,kw,ti.	2723
21	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20	282495
22	mouth hygiene/	21706
23	mouthwash/	3342
24	toothpaste/	7064
25	(mouth adj3 (health* or care or hygiene)).ab,kw,ti.	923
26	(oral adj3 (health* or care or hygiene)).ab,kw,ti.	35184
27	(dental adj3 (health* or care or hygiene)).ab,kw,ti.	24046
28	(tooth adj3 (health* or care or hygiene)).ab,kw,ti.	692
29	(teeth adj3 (health* or care or hygiene or clean*)).ab,kw,ti.	2367
30	(mouthwash* or mouthrinse*).ab,kw,ti.	3818

31	(mouth adj3 (wash* or rins* or swab*)).ab,kw,ti.	1817
32	(toothpaste* or tooth-paste or dentifrice* or toothbrush*).ab,kw,ti.	9457
33	((tooth or teeth) adj3 brush*).ab,kw,ti.	3114
34	dry mouth.ab,kw,ti.	6415
35	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34	81720
36	21 and 35	1472

Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Date searched: 31/08/17

#	Searches	Results
1	terminal care/	25990
2	palliative care/	49967
3	hospice care/	6244
4	"hospice and palliative care nursing"/	401
5	terminally ill/	6382
6	nursing homes/	32385
7	(end* adj3 life).ab,kw,ti.	22617
8	(last year adj3 life).ab,kw,ti.	558
9	(terminal* adj3 (cancer* or ill* or disease* or care or healthcare)).ab,kw,ti.	12046
10	(palliative adj3 (cancer* or care or healthcare)).ab,kw,ti.	24502
11	(dying adj3 patient*).ab,kw,ti.	6292
12	(close adj3 death).ab,kw,ti.	549
13	(hospice* adj3 (care* or healthcare)).ab,kw,ti.	5131
14	nursing home*.ab,kw,ti.	27626
15	end stage.ab,kw,ti.	57555
16	terminal stage.ab,kw,ti.	2143
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	200214
18	oral hygiene/	11954
19	oral health/	13297
20	exp dental care/	30915
21	toothpaste/	3077
22	(mouth adj3 (health* or care or hygiene)).ab,kw,ti.	755
23	(oral adj3 (health* or care or hygiene)).ab,kw,ti.	34586
24	(dental adj3 (health* or care or hygiene)).ab,kw,ti.	23717
25	(tooth adj3 (health* or care or hygiene)).ab,kw,ti.	664
26	(teeth adj3 (health* or care or hygiene or clean*)).ab,kw,ti.	2346
27	(mouthwash* or mouthrinse*).ab,kw,ti.	3546
28	(mouth adj3 (wash* or rins* or swab*)).ab,kw,ti.	1561
29	(toothpaste* or tooth-paste or dentifrice* or toothbrush*).ab,kw,ti.	9890
30	((tooth or teeth) adj3 brush*).ab,kw,ti.	2991
31	dry mouth.ab,kw,ti.	4372
32	18 or 19 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31	76517
33	17 and 32	1117

Appendix 6: Excluded articles at the full-text stage with justification – Qualitative systematic review

Excluded papers	Justification
1. Aldred et al., 1991 Oral health in the terminally-ill: a cross-sectional pilot survey.	Quantitative study
2. Anonymous, 2014 Considering the need for dental plans in end-of-life palliative care.	Letter
3. Anonymous, 2014 Dental treatment in chronically ill adults in last year of life.	Review of a paper
4. Barker et al., 2005 Current practice and knowledge of oral care for cancer patients: a survey of supportive health care providers.	Quantitative study – despite claiming in the methods section the use of questionnaires with both close-ended and open-ended questions – there was no qualitative analysis of the questions as claimed.
5. Beigi, 2012 Dentists as leaders of teamwork in palliative care for the patients with head and neck cancer.	Abstract only
6. Berkey et al., 1987 Is there a role for dental professionals within hospice programs?	Narrative review
7. Carlson, 2012 End of life: survey shows the many ways caregivers can help beyond providing medication.	Opinion paper
8. Cartwright et al., 2006 Symptom experiences of residents dying in assisted living.	Paper does not mention any form of oral care. Reports symptoms, namely oral symptoms.
9. Chen et al. 2013 Dental treatment intensity in frail adults in the last year of life.	Quantitative study
10. Chen et al. 2013 Self-reported oral health and oral health behaviors in older adults in the last year of life.	Quantitative study
11. Chen and Kistler, 2015 Oral health care for older adults with serious illness: when and how?	Editorial

<p>12. Condelius and Anderson, 2015</p> <p>Exploring access to care among older people in the last phase of life using behavioural model of health services use: a qualitative study from the perspective of the next of kin of older persons who had died in a nursing home.</p>	<p>Paper does not mention any form of oral care/ mouth care, only access to dental care in the form of dental visits. No mention of any form of dental treatment either.</p>
<p>13. Davies, 1998</p> <p>Mouth care and skin care in palliative medicine. Clinically proved treatments for xerostomia were ignored.</p>	<p>Letter to editor</p>
<p>14. Dixon and Hockley, 1998</p> <p>Mouth care and skin care in palliative medicine. Simple antiseptic mouthwashes are best for infection.</p>	<p>Letter to editor</p>
<p>15. Ezenwa et al., 2016</p> <p>Caregivers' perspectives on oral health problems of end-of life cancer patients.</p>	<p>Quantitative study</p>
<p>16. Fitzgerald and Gallagher, 2018</p> <p>Oral health in end-of-life patients: A rapid review.</p>	<p>Rapid review</p>
<p>17. Fowell et al., 2002</p> <p>An integrated care pathway for the last two days of life: Wales-wide benchmarking in palliative care.</p>	<p>Paper does not mention any form of oral care.</p>
<p>18. Frenkel et al., 2000</p> <p>Oral health care among nursing home residents in Avon.</p>	<p>Not population of interest i.e. palliative care patients</p>
<p>19. Garelius and Anderson, 2012</p> <p>Dying in a haematological unit: Experiences based on the Swedish palliative registry.</p>	<p>Abstract only (7th World Research Congress of the European Association for Palliative Care)</p>
<p>20. Gomez-Batiste et al., 2001</p> <p>Cancer death in Catalonia: Population study about the last month of life in cancer patients (1993-94).</p>	<p>Not in English language</p>
<p>21. Hoeksema et al., 2017</p> <p>Oral health status and need for oral care of care-dependent indwelling elderly: from admission to death.</p>	<p>Not obvious that these adults are receiving palliative care</p>
<p>22. Ito et al., 2015</p> <p>Oral care in palliative care center reduces salivary amylase activity, a marker of stress condition.</p>	<p>Abstract only</p>
<p>23. Jucan and Saunders, 2015</p> <p>Maintaining oral health in palliative care patients.</p>	<p>Narrative review</p>
<p>24. Kang et al., 2010</p>	<p>Not in English language</p>

Effects of oral care with essential oil on improvements in oral health status of hospice patients.	
25. Kayser-Jones et al., 2003 Factors that influence end-of-life care in nursing homes: the physical environment, inadequate staffing, and lack of supervision.	Oral care and/or oral health not the main topic
26. Kelsch, 2009 Hospice hygiene: oral comfort care for end-of-life patients.	Opinion paper
27. Kerr, 1989 Mouth care for the dying.	Opinion paper
28. Kristanti et al., 2017 Enhancing the quality of life for palliative care cancer patients in Indonesia through family caregivers: a pilot study of basic skills training.	Oral care and/or oral health not the main topic
29. Kvalheim et al., 2016 End-of-life palliative oral care in Norwegian health institutions. An exploratory study.	Quantitative study
30. Lee et al., 2001 An audit of oral care practice and staff knowledge in hospital palliative care.	Quantitative study
31. Lucas and Roberts, 1998 Mouth care and skin care in palliative medicine. Chlorhexidine mouth washes are important in mouth care.	Letter to editor
32. Lundstrom and Fransson, 2014 Improvements in quality of end-of-life care in Sweden – updated results from the Swedish register of palliative care.	Abstract only (8 th World Research Congress of the European Association for Palliative Care)
33. Macpherson, 2013 Dry mouth management in palliative and cancer care.	Narrative review
34. McCann et al., 1994 The appropriate use of nutrition and hydration.	Oral care and/or oral health not the main topic
35. McMillan et al., 2013 The COPE intervention for caregivers of patients with heart failure.	Paper does not mention oral care.
36. Mercadante et al., 2000 The impact of home palliative care on symptoms in advanced cancer patients.	Paper does not mention any form of oral care. Reports symptoms, namely oral symptoms.
37. Mills et al., 1994 Care of dying patients in hospital.	Paper does not mention any form of oral care.
38. Mukerji et al., 2017	Abstract only (presentation)

A clinical audit of xerostomia assessment and treatment practices amongst advanced cancer patients in a palliative care setting.	
39. Munn et al., 2006 Is hospice associated with improved end-of-life care in nursing homes and assisted living facilities?	Paper does not mention any form of oral care.
40. Nakajima et al., 2015 Oral care in palliative care settings – actual situation of oral problems and issues from the view point of “total pain”.	Abstract only (presentation)
41. Nakajima, 2017 Characteristics of oral problems and effects of oral care in terminally ill patients with cancer.	Quantitative study
42. Nitschke et al., 2010 Dental care of frail older people and those caring for them.	Not obvious that these adults are receiving palliative care
43. Oh et al., 2014 Palliative dental care for metastatic breast cancer patients during active anticancer treatment.	Abstract only
44. Ohno et al., 2016 The need and availability of dental services for terminally ill cancer patients: a nationwide survey in Japan.	Oral care and/or oral health not the main topic
45. Paska et al., 2009 Improving clinical based practice in mouth care.	Abstract only (poster presentation)
46. Ps and Mahan, 2015 Oral care in terminally ill patients, a semi-structured interview of oral medicine specialist in Kerala, India.	Abstract only
47. Rohr et al., 2012 Oral discomfort in palliative care: results of an exploratory study of the experiences of terminally-ill patients.	Same paper published 2 years earlier in different journal
48. Schimmel et al., 2008 Utilisation of dental services in a university hospital palliative and long-term care unit in Geneva.	Oral care and/or oral health not the main topic
49. Scully et al. 2004 Oral mucositis: a challenging complication of radiotherapy, chemotherapy and radio-chemotherapy. Part 2: Diagnosis and management of mucositis.	Narrative review
50. Simoes et al., 2009 Care of dying in an oncologic palliative care unit.	Abstract only (poster presentation)
51. Sweeney et al., 1996 Provision of mouth care by nursing staff for cancer patients in Scotland: current status and the role of training.	Quantitative study

52. Trevisani et al., 2016 Oral health assessment of cancer patients in exclusive palliative care in Barretos cancer hospital, Brazil.	Abstract only
53. Van Lancker et al., 2017 Frequency and intensity of symptoms and treatment interventions in hospitalised older palliative cancer patients: a multicentre cross-sectional study.	Only describes oral symptoms
54. Verreault et al., 2017 Quasi-experimental evaluation of a multifaceted intervention to improve quality of end-of-life care and quality of dying for patients with advanced dementia in long-term care institutions.	Paper does not mention a form of oral/mouth care. Mouth care is mentioned, but it is not stated what form of mouth care.
55. Waldrop and Kirkendall, 2009 Comfort measures: a qualitative study of nursing home-based end-of-life care.	Paper does not mention a form of oral/mouth care.
56. Wilberg et al., 2012 Oral health is an important issue in end-of-life cancer care.	Paper does not mention a form of oral/mouth care.
57. Wilson et al., 2013 Quantitative analysis of formal caregivers' use of communication strategies while assisting individuals with moderate and severe Alzheimer's disease during oral care.	Not population of interest.
58. Wilwert et al., 2011 The involvement of Iowa dentists in hospice care.	Not population of interest. Paper about dentists and the factors associated with the involvement of dentists in hospice care
59. Wyche and Kerschbaum, 1994 Michigan hospice oral healthcare needs survey.	Quantitative study

Appendix 7: Approval letter from the Chair of the Research Ethics Committee

RESEARCH WITH PLYMOUTH UNIVERSITY

17th April 2018

CONFIDENTIAL

Maria Bernardes Delgado
C507 Portland Square
Peninsula Dental School
Plymouth University
Drake Circus
Plymouth
PL4 8AA

Dear Maria,

Application for Approval by Faculty Research Ethics and Integrity Committee

Reference Number: 17/18-908

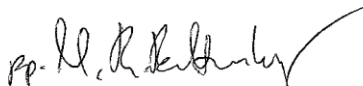
Application Title: The oral care experiences of palliative care patients
in a hospice in the South-West of England. A qualitative study.

I am pleased to inform you that the Committee has granted approval to you to
conduct this research.

Please note that this approval is for the duration of your project as stated on
your application form (1st April 2018 to 31st December 2018), after which you
will be required to seek extension of existing approval.

Please note that should any MAJOR changes to your research design occur
which effect the ethics of procedures involved you must inform the
Committee. Please contact Maurice Bottomley (email
hhsethics@plymouth.ac.uk).

Yours sincerely



Professor Paul H Artes, PhD MCOptom
Professor of Eye and Vision Sciences
Co-Chair, Research Ethics Committee -
Faculty of Health & Human Sciences and
Peninsula Schools of Medicine & Dentistry

Appendix 8: Letter of support from the Chair of the Quality and Patient Safety



Director of Patient Care
Hospice

Wednesday 28th February 2018

Maria Bernardes Delgado
Academic Clinical Fellow in Primary Dental Care
Plymouth University Peninsular Schools of Medicine and Dentistry
John Bull Building
Science Park, 8BU
Research Way
Plymouth
Devon
PL6 8BT

Dear Maria

I am writing to inform you that your research proposal was reviewed and discussed at our Quality and Patient Safety meeting on 22nd February 2018.

The Committee were pleased to approve your proposed study in principle, subject to two minor suggested amendments:

1. The term 'terminally-ill patients' is replaced with 'palliative care patients' - the reason for this is that 'terminally ill' is a phrase open to all sorts of interpretation and feels a bit out-dated and most importantly could be upsetting for patients'. 'Palliative care patients' would be a more sensitive approach for patients and their families.
2. The duration of the semi-structured interviews is amended to approximately 30 minutes - the reason for this is that patients seeing that the experience could last 'up to an hour' could potentially put them off, due to fatigue etc.

We would also appreciate seeing evidence of your university insurance indemnity for your research and a copy of your ethics approval prior to you commencing data collection at the hospice site.

We wish you the very best with this important research study and look forward to reviewing the findings.

Yours sincerely

A redacted signature.

Dr [Redacted]
Director of Patient Care/Chair of Quality & Patient Safety Committee

Appendix 9: Participant information sheet



Information Sheet

Title of project: The oral care experiences of palliative care patients in a hospice in the South-West of England. A qualitative study.

You are being invited to participate in a research project. Before you decide whether you are happy to do so, please read the information sheet carefully.

What is the purpose of this study?

This study will give us important insight into a poorly researched area: the oral care of palliative care patients. Oral symptoms are amongst the most common problems palliative care patients face. However oral care is not always adequate and there is a certain degree of confusion surrounding palliative oral care. In addition the perspective of patients, their relatives and frontline healthcare professionals regarding the oral care provided is rarely sought. Therefore we aim to explore the oral care experiences of palliative care patients from their point of view and from the perspectives of their relatives and those providing oral care.

Why have I been invited to take part?

You have been invited to take part in this study, because you are either an inpatient at [REDACTED] hospice or you are a relative of an inpatient at [REDACTED] hospice or you are a frontline healthcare professional who provides oral care. We are interested in your views and experiences regarding the oral care received or provided.

Do I have to take part?

Your decision to take part in this study is entirely voluntary. You can withdraw at any time during the study, without providing any reason, and this will not affect your care, the care of your relative or your position.

What would taking part involve?

Your participation in the study will take approximately 30 minutes. I will ask you a few questions regarding your oral health and oral care experiences. If you are a relative or frontline healthcare professional I will ask you about the oral health and oral care experiences of your relative or the patient you care for.

The interview will take place at [REDACTED] hospice, it will be one-one and it will be audio-recorded.

What are the other possible disadvantages and risks of taking part?

During the interview you will be talking about issues that may cause you distress and anxiety. If this occurs the interview will be stopped and you may withdraw from the study. In such a case, you will be assisted in finding appropriate and immediate support.

Version 3.0, 15th May 2018

**What are the possible benefits of taking part?**

You will be able to contribute towards research and perhaps help others who experience similar problems and difficulties.

Once the data of the study have been anonymised and analysed, you will have the opportunity to receive a brief summary of the results of the study.

What if there is a problem?

If you have any concerns regarding the conduct of this study or you wish to complain please contact:

Professor Liz Kay (Director of Studies)
Associate Dean for Equality and Inclusion/ Foundation Dean Peninsula Dental School
Room C520, Portland Square
Plymouth, PL4 8AA
elizabeth.kay@plymouth.ac.uk

If your concerns have not been resolved after speaking to Professor Liz Kay, please contact the Research Administrator to the Faculty Research Ethics Committee:

Maurice Bottomley
Faculty of Health and Human Sciences
4th Floor Rolle Building, Drake Circus
Plymouth PL4 8A
hhsethics@plymouth.ac.uk.

Will my taking part in the study be kept confidential?

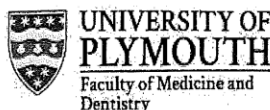
Your interview will be made anonymous. Your name will only be used in the consent form to keep a record of those who agreed to take part in the study. A unique study number will be given to you to record your interview and to analyse the data. Your answers will be kept confidential at all times and treated with respect. Any data and results included in future publications will remain anonymous too.

What will happen if I don't want to carry on with the study?

Your decision to take part in this study is entirely voluntary. You can withdraw at any time during the study. Please let the principal investigator (MBD) know you wish to withdraw. Your data will not be used for analysis and it will be destroyed. Once your data is anonymised with a unique identifier, it will not be possible to withdraw your anonymised data.

What will happen to the results of the research study?

The results of the study will be used in a thesis document (for the principal investigator's Research Masters). They will also be disseminated within the dental and palliative care research community via peer-review publications and conference presentations. A brief report of the findings will be made available to you. You will not be able to be identified in any of the write up or publications.



Who is organising the research?

The research is funded by the National Institute for Health Research (NIHR) and sponsored by the University of Plymouth.

Who has reviewed the study?

The study has been reviewed by the Plymouth University Faculty Ethics Research Committee.

Thank you for reading the participant's information sheet for the present study.

With kind regards,

Maria Bernardes Delgado BDS, MPH, MJDF RCS (Eng), FHEA
Principal Investigator, NIHR Academic and Clinical Fellow in Primary Dental Care
Peninsula Dental School, Plymouth University (PUPSMD)
C507 Portland Square
University of Plymouth
Plymouth PL4 8AA
Email: mariadocarmo.bernardesdelgado@plymouth.ac.uk
Mobile: 07729563507
Research webpage: <https://www.plymouth.ac.uk/research/oral-health-and-palliative-care-in-the-uk>

In order to decide whether I want to take part in the study "*The oral care experiences of palliative care patients in a hospice in the South-West of England. A qualitative study*";

I agree that my contact details can be shared with the principal investigator (MBD) by the team at [REDACTED]

I am a patient/ relative/ healthcare professional (please delete as applicable).

Name

Date

Signature

Appendix 10: Consent form



CONSENT FORM

Title of project: "The oral care experiences of palliative care patients in a hospice in the South-West of England. A qualitative study."

Participant Identification Number:
Name of Researcher: Miss Maria Bernardes Delgado
Director of studies: Professor Liz Kay

Please tick the relevant boxes

1. I confirm that I have read the information sheet (version 3 date: 15/05/2018) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.
3. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.
4. I agree that some demographic data will be collected anonymously.
5. I agree to take part in the above study.

☐☐☐☐☐

Name of participant

Date

Signature

Name of person
taking consent

Date

Signature

Appendix 11: Interview guide

The oral care experiences of palliative care patients in a hospice in the South-West of England. A qualitative study.

Interview guide

Introduction

- MBD will tell participants about her background as a dentist and as an ACF at Plymouth University;
- As part of her masters in research MBD is undertaking this project with the aim to explore the oral care experiences of palliative care patients;
- MBD will ask participants whether they are happy for the interview to be recorded;
- MBD will inform participants that if at any point they wish to stop, the interview will be terminated.

- **Topic guide (patients)**

Thank you for agreeing to talk to me today, before we get to my questions was there anything in particular that you wanted to say?

- I would like to start by asking you how are you feeling physically today?

Comfortable? / In pain?

- What about your teeth? How do your teeth feel today?
- What about your mouth? How does your mouth feel today?
- Are you experiencing any of the following: dry mouth, pain, difficulty swallowing, difficulty to eat, difficulty to taste food, problems communicating, concerns about mouth appearance?
- Do your mouth/ teeth feel different today to how they felt last week?
- How does it feel different?
- Do you know why it might feel different?

Thank you for telling me about how your mouth and teeth feel. I would now like to ask you about what is done to look after them.

- Who looks after your teeth/ mouth at the hospice?
- Who looks after your teeth/ mouth at home?

- What do they/you do to look after your teeth/ mouth?
 - *Tooth brushing? Rinsing with mouthwash?*
- How do you find that?
 - *Easy? Painful? Important? Waste of time?*
- Are there any examples of things that you found useful or went really well regarding your mouth care since you've been not so well? Or the opposite?
- Is there anything that could be done to improve your oral health? The way your mouth and teeth feel?
- How important is caring for your mouth for your overall health? Why?
- **Thank you very much for answering everything I wanted to ask you, is there anything you would like to ask me?**
- **Is there anything you were hoping to say today that you haven't had the chance to say yet?**

- **Topic guide (healthcare professionals)**

Thank you for agreeing to talk to me today, before we get to my questions was there anything in particular that you wanted to say?

- Generally, what do you think patients feel about the condition of their teeth/mouths when they are in the hospice?
- What do you think their relatives/friends think?
- How important is the condition of their mouths/teeth to your patients?
- And for their relatives/friends?
- How important is the condition of your patients' mouths and teeth to their overall wellbeing?
- How important is mouth care to them? And to you?

I'd like to know a little bit about how your patients' mouths and teeth are looked after.

- Who usually looks after your patients' mouths and teeth?
- When you are delivering this care what would you usually do?
- How often would you do that?
- Are there any reasons which would mean you wouldn't carry out that care?
- Have you received any training?

Tooth brushing? Rinsing with mouthwash?

- Is there anything that would improve your skills/ confidence in caring for your patients' mouths?
- How do you find delivering these procedures?
 - *Barriers/facilitators?*
- How do you think your patients feel about these procedures?
 - *Easy? Painful? Important? Waste of time?*
- Are there any examples of things that you found useful or went really well regarding the mouth care provided to your patients? Or the opposite?
- In your opinion is there anything that could be done to improve the oral health of your patients? The way their mouth and teeth feel?

Thank you very much for answering everything I wanted to ask you, is there anything you would like to ask me?

Is there anything you were hoping to say today that you haven't had the chance to say yet?

- **Topic guide (relatives)**

Thank you for agreeing to talk to me today, before we get to my questions was there anything in particular that you wanted to say?

- Generally, what do you think your relative feels about the condition of his/her teeth/ mouth?
- What do you think about the condition of his/her teeth/mouth?
- How do you feel about the condition of his/her teeth/mouth?
- How important is the condition of his/her mouth to your relative?
- And for you?
- How important is the condition of your relative's mouth and teeth to his/her overall wellbeing?
- How important is mouth care to them? And to you?

I'd like to know a little bit about how your relative's mouth and teeth are looked after.

- Who usually looks after your relative's mouth and teeth at the hospice? And at home?
- If you were/ are delivering this care what would you usually do?
- How often would you do that?
- Are there any reasons which would mean you wouldn't carry out that care?

- Have you received any training?
 - Tooth brushing? Rinsing with mouthwash?*
- Is there anything that would improve your skills/ confidence in caring for your patients' mouths?
- How do you find delivering these procedures? (if applicable)
 - *Barriers/facilitators?*
- How do you think your patients feel about these procedures?
 - *Easy? Painful? Important? Waste of time?*
- Are there any examples of things that you found useful or went really well regarding the mouth care provided to your relative? Or the opposite?
- In your opinion is there anything that could be done to improve the oral health of your relative? The way their mouth and teeth feel?

Thank you very much for answering everything I wanted to ask you, is there anything you would like to ask me?

Is there anything you were hoping to say today that you haven't had the chance to say yet?